DOCUMENT RESUME

ED 225 893 SO 014 458

AUTHOR Levine, Carol, Ed.; Veatch, Robert M.
TITLE Cases in Bioethics from the Hastings Center Report.
INSTITUTION Hastings Center, Hastings-on-Hudson, NY.
REPORT NO ISBN-0-916558-17-7
PUB DATE 82
NOTE 123p.; Some pages may not reproduce clearly in microfiche due to light print type.
AVAILABLE FROM Hastings Center, 360 Broadway, Hastings-on-Hudson, NY 10706 ($7.95, $6.95 for ten or more).
PUB TYPE Viewpoints (120) -- Collected Works - General (020)

EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS Abortions; Adult Education; Case Studies; Conflict Resolution; Controversial Issues (Course Content); Critical Thinking; Death; *Ethical Instruction; Ethics; Higher Education; Medical Services; Mental Health; *Moral Issues; *Moral Values; Physician Patient Relationship; Public Policy; Reproduction (Biology); *Social Problems; Values Education
IDENTIFIERS *Bioethics; Human Subject Protection

ABSTRACT

Case studies of ethical issues based on real events are followed by comments illustrating how people from various ethical traditions and frameworks and from different academic and professional disciplines analyze the issues and work toward a resolution of the conflict posed. The cases are intended to help the public and professional persons pursue reflective, well-thought-out solutions to real human moral dilemmas, using a systematic ethical analysis. There are seven chapters. The case studies in chapter 1, on issues in reproduction, treat abortion, population programs, risk taking and birth defects, sterilization, and rape. Chapter 2, on patient-physician relationships, examines homosexuality, choosing a therapy when doctors disagree, and faith healing for childhood leukemia. Mental health and medical interventions are the topics of the third chapter. Euthanasia, nurturing a defective newborn, organ donation, and family wishes and patient autonomy are examples of topics treated in chapter 4 on death and dying. Chapters 5 and 6 examine human subjects research and the allocation of scarce (health) resources. The concluding chapter deals with public policy and includes cases on laetrile, baby making, anti-aging drugs, drinking on the job, and state legislation regarding child passenger protection. (RM)

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Cases in Bioethics

from THE HASTINGS CENTER REPORT

Edited by

Carol Levine and Robert M. Veatch

SP014 458

THE HASTINGS CENTER • HASTINGS-ON-HUDSON, NEW YORK

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The Hastings Center
Institute of Society, Ethics and the Life Sciences
360 Broadway
Hastings-on-Hudson, New York 10706

Library of Congress Cataloging in Publication Data

Cases in bioethics from the Hastings Center Report

1. Medical ethics—Case studies. 2. Hastings Center Report. I. Levine, Carol. II. Veatch, Robert M. III. Hastings Center Report.
R724.C36 1982 174'.2 82-81217
ISBN 0-916558-17-7 AACR2

Printed in the United States of America

INSTITUTE OF SOCIETY, ETHICS AND THE LIFE SCIENCES

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Introduction

Since its founding in 1969 The Hastings Center has been committed to the idea that good work in applied ethics requires serious attention to both basic questions of ethical theory and to real-life, day-to-day problems of ethical decision making. Beginning with the first issue of the *Hastings Center Report* in 1971, case studies in bioethics and related fields of applied ethics have been a regular feature of the publication. Teachers, students, clinicians, workshop leaders, and many others have used these cases; and many have suggested that a collected volume would be useful. This volume contains all 42 cases published in the *Hastings Center Report* between 1975 and 1981.

All the cases are based on real events, in which critical decisions had to be made. Sometimes health care professionals—physicians, nurses, administrators, and others—had to make these decisions; but often the ethical dilemmas were posed for medical lay people—patients, their families, judges, public officials, and others. Some cases contain undisguised information including real names of participants. These cases are based entirely on information in the public record. "Can Convicts Consent to Castration?", "Interns and Residents on Strike", and "Laetrile: Cancer Cure or Quack Remedy?" are examples. In other cases confidential sources have been used, and names and details have been changed both to provide anonymity and greater clarity of the ethical issues.

The objective of presenting the cases has never been to expose ethical outrages or to point to a clear ethical solution to a problem. Occasionally an individual reader may be convinced that a course of action being contemplated is outrageous or that there is a clear, definitive ethical answer to the problem raised. It is certainly true that in some ethical situations rather clear ethical answers exist. We have, however, in selecting case studies, sought out more difficult cases where there appears to be room for reasonable people to disagree.

The commentators on the cases were selected to illustrate how thoughtful people from various ethical traditions and frameworks and from different academic and professional disciplines analyze the issues and work toward a resolution of the conflict posed in the case. Many times commentators have pleaded that the cases seem irresolvable. We have been pleased with that response and especially pleased when the commentators have then gone on to tell us what they would do, faced with such dilemmas, giving us the reasoning that leads them to their conclusions. It is that pursuit of reflective, well-thought-out solutions to real human moral dilemmas based upon more systematic ethical analysis that is the goal of the presentation of these cases.

For this volume, we have organized the cases into categories chosen to provide some continuity in reading, and to emphasize the primary focus of the case. Still, as in any case collection, the groupings are somewhat arbitrary. Many cases have more than one ethical dimension, and they can be found under thematic headings that may not at first seem obvious. For example, those interested in studying cases dealing with death and dying should explore in addition to the section entitled "Death and Dying," sections such as "Allocation of Scarce Resources" where two cases, "Forced Transfer of Custodial Care" and "Refusing an Amputation," deal with resource allocation for the terminally ill. They should also see the chapter on "Mental Health and Medical Interventions" for the case. "'Ain't Nobody Gonna Cut on My Head!,' " for an exploration of the psychiatric complications of a potentially fatal treatment refusal of surgery for a brain tumor.

For some cases the authors are identified with bylines. Cases not otherwise identified were written by Robert Veatch, Carol Levine, other staff of The Hastings Center, or by individuals who choose to remain anonymous.

The cases are reproduced in this volume exactly as they appeared in the *Report*,

with a few minor exceptions: (1) all the titles have been reset for typographical consistency; (2) all extraneous material that appeared on the pages has been deleted; (3) all the identifications of contributors have been deleted. An up-to-date list identifying all contributors appears on pages viii-ix. In one case, "Dialysis for Schizophrenia: Consent and Costs," p. 175, a postscript has been added by one of the case commentators.

Over the years many people at The Hastings Center have contributed to the development of the case studies. We would especially like to thank Daniel Callahan, Director of the Center, and Arthur Caplan, Associate for the Humanities. During part of the period covered in this volume Peter Steinfels and Margaret O'Brien Steinfels were, jointly and singly, editors of the *Report*; they contributed significantly to the cases published during their tenures. Others have devoted their editorial, research, and administrative skills, among them Linda Asher, Nancy Taylor, Ira D. Singer, and Ernest Tai. We would especially like to thank the present editorial staff of the *Hastings Center Report*—Joyce Bermel, managing editor; Nancy deKoven, production manager; and Barbara Hopkins, editorial assistant. Special thanks are due to Marna Howarth, the Center's librarian, who has ably assisted in preparing this collection for publication. Our greatest debt is to all the contributors of this volume—those authors and commentators who have reflected on these hard cases and have shared their conclusions with our readers.

C.L. and R.M.V.

1

Issues in Reproduction

The Unwanted Child: Caring for the Fetus Born Alive After an Abortion

Last spring the California State Legislature passed a bill specifying that a viable fetus which is live-born following an abortion or attempted abortion is a ward of the state. Furthermore, the bill required that physicians performing abortions must take "all reasonable steps, except extraordinary means, in accordance with good medical practice, to preserve the life and health of the live-born person." However, the bill also specified that it was not to be construed as granting priority to the live-born person over its mother with respect to the provision of lifesaving medical treatment.

The bill defined a "viable fetus" as one which is biologically viable, based on the consideration of a minimal number of independently sustained, basic, integrative functions. The viable fetus is able to (1) increase in tissue mass, (2) increase the number, complexity, and coordination of basic physiological functions, and (3) develop into a self-sustaining whole organism independent of any connection with the mother. A "fetus" would be considered a live-born person if, outside the womb, it manifests a sustained heartbeat, umbilical pulsation, spontaneous respiration, and movement of voluntary muscles.

In addition to any criminal or civil liability which may be imposed by law, any violation of the law would constitute unprofessional conduct under the State Medical Practice Act.

In August the bill was amended and sent to Governor Edmund G. Brown Jr. in this form: "The rights to medical treatment of an infant prematurely born alive in the course of an abortion shall be the same as the rights of an infant of similar medical status prematurely born spontaneously." Three of the commentators whose views are presented here (Walters, Nathan, Nathanson) also presented written testimony on the bill.

The bill was signed by the governor in its amended form, as part of the California Health and Safety Code, in September.

COMMENTARY

by SISSELA BOK

We are asked to imagine the following irrational behavior. First, medical personnel and a pregnant woman cooperate in abortive practices usually fatal to an embryo or fetus. But, if by chance the fetus survives their assault, they proceed to do everything in their power to sustain its flickering life. This is what the California assembly bill requires. It allows abortions to proceed, then it declares a live-born product of the abortion to be a ward of the state, and requires what it calls "all reasonable steps" to be taken to preserve its life and health.

Some will conclude that the first activity, the abortion, was wrong from the outset; for them the proof is that a reversal is required when the effort fails. They will argue that consistency demands that all fetuses be treated as patients throughout pregnancy.

Others will argue, on the contrary, that it is right and lawful to perform the abortion, and that what is irrational is to reverse directions in midstream, without carrying the act of abortion to its intended end.

We have then two polarized opinions. But this polarization depends on a blurring of important moral distinctions. We need to ask two questions: what should be done in cases of live-born aborted fetuses? and what social policies can prevent these dilemmas from occurring in the first place?

My premise, in answering these two questions, is that women must be allowed to have early abortion on request. Few will deny that there is a basic need for families and individuals to control their fertility. While I consider contraception, abstinence, and sterilization to be preferable to abortion as birth prevention, it is sometimes too late to use such methods. Many are beginning to forget the inevitability of the choice previously confronting most women who were pregnant against their wishes—the choice between a dangerous, uncertain, and unlawful abortion, and the terrors and burdens and ruined lives which have afflicted so many: maternal weakness or death from childbirth, children for whom no one had the strength or the resources to care adequately, young girls bringing babies to the world without having had a childhood of their own.

Given this premise then, what would I advocate doing if a live-born fetus results from an abortion? First, I think we have to set aside as irrelevant the fact that such births are rare. This fact does not eliminate the moral dilemma which exists whether there is one victim or ten thousand.

Take a very clear case and undoubtedly a very unusual one. Say that a hysterotomy has been performed on a woman who mistakenly reports that she is in her sixth month of pregnancy and that an intact 4-pound live-born baby emerges from this operation. There can be no question, it seems to me, that in such a case the baby ought to be treated and cared for like any newborn, with the appropriate supportive techniques. If we can agree with respect to this one, admittedly unusual, case, then I believe that we have necessarily concluded that it is not the fact of abortion which should in itself determine the fate of the premature baby.

At this point you may well think that I have landed myself in a contradiction: I believe that abortion can be justified; yet am I not also saying that fetuses *are* to be treated as patients? If so, how can they be aborted in the first place?

The way out of this seeming contradiction is to stress that while a woman does have the right to an abortion in the sense of the termination of her pregnancy, she does not have the right to the death of the fetus. The termination of early pregnancy carries with it, at present, fetal failure to survive. But in later pregnancy, where abortion and death of the fetus do not necessarily go together, it is a fallacy to believe that a right to the first also implies a right to the second. I can maintain, then, without contradiction, that abortion is justified, but that if a live birth should result, it must be protected.

But let us now return to the realities of abortions. If a fetus survives an abortion there will be every reason to fear that it has been severely damaged by the procedure itelf and that it will be further damaged by efforts to maintain its life. As a result, any law requiring the maintenance of life in such survivors might result in extraordinary suffering on the part of those who are rescued. The effort to maintain life might well then constitute battery.

In cases of life resulting from abortions, medical personnel should therefore be allowed and expected to exercise the same judgment as they do with prematurely born babies. But they *must* be allowed to make a realistic appraisal of the chances of survival and of quality of life after the abortive procedures, and not be forced by legislation and fear of repercussions into providing care they would never give to similarly burdened prematures. Insofar as it would inspire such fears, the California legislation is unwise.

Now to the second question: what social policies can help individuals to avoid such dilemmas in the first place? For the best way out is obviously not to fall into this tragic predicament in the first place.

In many nations which permit abortion, such dilemmas are largely avoided, for the simple reason that late abortions are prohibited. Abortion on request is permitted in these societies only during the first trimester and later only under very special circumstances.

But in this country, we have no such clear guidelines. As a result, we encounter agonizing dilemmas; and our abortion debate is much inflamed by the thought of viable or nearly viable fetuses subjected to abortion. Why does our society have this special dilemma? The root of the problem lies in one provision of the *Roe* v. *Wade* decision by the United States Supreme Court, striking down a statute which prohibited abortion: it set no clear time limit in pregnancy after which abortions should no longer be performed. It merely declared that states may, if interested in protecting

fetal life after viability, proscribe abortion (except in cases of threat to the life or health of the mother).

This may be all that could be done on constitutional grounds. But it left the abortion situation in the United States extraordinarily open-ended. I believe that we, as a society, must now arrive at a time limit in pregnancy after which most abortions are out of the question. Needless to say, however, such a social choice should not be exercised retroactively so as to punish those having performed abortions lawful at the time.

If such a time limit is set, questions of viability will not come up. Legislation such as California Assembly Bill 2346 will be unnecessary. And much greater social efforts to help individuals cope *before* pregnancy with unwanted fertility will have to be undertaken.

If given a choice between accepting the California assembly bill and rejecting it, therefore, I would definitely reject it. But I would wish to work for improved and careful social policies limiting late abortions. For stumbling and imprecise as this California legislation is, it does represent an effort to respond to the present failure of our institutions to set such limits.

COMMENTARY

by BERNARD N. NATHANSON

When we first began to do abortions on a large scale following the passage of the 1970 New York statute, the question of the fate of the (accidentally) live-born fetus was an unanswerable argument consistently brought up by antiabortion factions. It was not really a medical dilemma; we reacted by placing these infants in the appropriate nursery facility. But it *was* a moral dilemma, and the pro-abortion group for the most part simply had no response.

The dimensions of this dilemma were exemplified by the *Edelin* case, which was a profound misunderstanding. Dr. Edelin regrettably labored under the same misapprehension that a great many obstetricians and pro-abortion advocates have labored under: that abortion necessarily implies the death of the products of conception. It does not now and it never did. Abortion merely intends to remove the products of conception from the unwilling host. And if one views abortion in that way—namely, that the woman's rights as the unwilling host are respected and that the products of conception are removed —then the fetus's rights (and it *does* have rights regardless of the Supreme Court's meaning within the Fourteenth Amendment) are also respected in that it is removed and cared for in the best manner possible.

Obstetricians and gynecologists are well aware of the increasing number of fetuses which are born alive, because of the increased use of prostaglandins. In order to respect everyone's rights, the fetus should be removed from the uterus and then placed in the appropriate nursery environment. However, two technological advances would be required: (1) a huge leap forward to permit the fetus to be removed from the uterus in such an atraumatic way that its existence would be spared, and that it would not be seriously damaged in the process; and (2) the availability in nurseries of sophisticated life-support systems to maintain even very small fetuses of perhaps six, eight, or ten weeks. I envision a time when this level of technology will be available to us.

However, I hope that there will be a parallel advance: that really efficient birth control means will be available and will be used; the immune sera which are being tested in India are promising. Such an advance would reduce the number of abortions to a manageable number. Instead of a million abortions a year, we would probably perform a thousand, two thousand, or five thousand. With fewer abortions, the few live-born fetuses could be placed in these life-support systems and raised at the expense of the state with little additional burden to the taxpayer.

I left the abortion arena two years after abortion became legal. As director of a perinatal unit in a hospital affiliated with a medical school, I began to face some perplexing questions which necessarily demanded answers from me not only in terms of patient care but in terms of moral questions. One of them is the question of when to interfere during a labor when the fetus is in distress. The implications for interference with respect to Caesarean section are sharp and clear *medically*, but what about the woman who has a 26-week pregnancy which is suddenly in jeopardy during the course of a labor? Do we take heroic measures, that is, do we do a Caesarean section, or do we simply stand by and allow this fetus to expire? What about 24 weeks? What about 20 weeks, or 15 weeks? There are very, very difficult questions to answer in this area.

A similar dilemma is the question of whom and when and how long to resuscitate in the delivery room. Do we spend 45 minutes with an endotracheal tube on a 400 gram fetus? Do we spend 2 hours? 10 minutes? These are judgments which regrettably often have to be made on the spot, and there are few guidelines.

The problem is further complicated by the distinction between the state of "fetushood" and the state of infancy. We now have rather interesting, but still crude, methods of monitoring and surveying the fetus, and even of treating it *in utero*. As a result we are coming to consider the fetus as an "intrauterine patient." We are, involuntarily, showing it a certain personhood; we have now been faced with the question of the identity of that intrauterine organism—its rights, its worth, its degree of humanity. We do not have very good guidelines here. And so we are faced in the delivery room, in the operating room, and in the labor room suites with the unpleasant and disagreebale task of triage: whom do we save? whom do we allow to die? It becomes quite as stark as that.

In the California bill certain attempts are made to identify the fetus,

to ascertain the degree of its humanity; there are allusions to things like independent activity, increasing complexity of fetal physiology, and so on.

I believe that we have to recognize the humanity of the fetus right from conception, and if we can demythologize the process of birth—view it just as another transition in the life cycle—then we are much more able to identify and respect the fetus. In the framework of abortion, the fetus's rights must be recognized and weighed against the rights of the pregnant female. These rights will become more urgent and more compelling as our technology becomes more sophisticated.

COMMENTARY

by DAVID C. NATHAN

I have tried to read this legislation in terms of the background in which I have been involved—in the abortion and fetal research issue, and the argument about research on the dying.

I find this statute well-meaning, decent, not particularly self-serving; but I think it derives from two totally unsupported assumptions: first, that in California there are a significant number of viable, midterm fetuses that are aborted and do not receive adequate medical support; and second, that individual California obstetricians cannot be trusted to use their own judgment in the matter of the appropriate application of so-called "reasonable" medical care for aborted fetuses. Almost all obstetricians I know do not abort viable fetuses; if they do produce a viable fetus during an abortion, it is an accident.

Now these assumptions lead to the generalizations which (1) make the aborted fetus a ward of the state, and (2) establish mandatory guidelines for the application of so-called "reasonable medical care," based on a tripartite definition of fetal viability. The first two definitions are totally nonspecific because they would apply to any fetus or even to a newborn. The third definition is one which is nearly impossible to codify within a legal framework. One merely needs to review the testimony at the Edelin trial to see how so-called "experts" disagree on criteria for self-sufficiency, as a result of differences in moral, religious, ethical, and scientific backgrounds.

Hence, if the bill becomes law, obstetricians delivering midterm abortuses would be at the mercy of the local prosecutors who could obtain indictments with relative ease because the disputed facts would require expert testimony before a jury in a courtroom. And that's really the problem—when the state gets into this complex area, judges just can't dismiss cases; there must be a trial with all of the nastiness that follows. Thus the proposed law, perhaps unwittingly, attacks *Roe* v. *Wade* in a novel fashion. It does not prevent a woman from having an abortion but it threatens her with a brain-damaged infant and her obstetrician with criminal charges. Perhaps the legislators hope that this will discourage abortion without attacking the Supreme Court decision.

The ethical and practical aspects of this bill interest me even more than the legal aspects. The bill forces obstetricians to deliver so-called "reasonable" medical care to all late, first-term and midterm aborted fetuses because the obstetrician cannot be certain that his diagnostic impression of no viability is always correct. Since *Suffolk* v. *Edelin* occurred in a far less medically litigious state than California, any sensible California obstetrician would incubate and place in an isolette all midtrimester and late first-trimester aborted fetuses. A tiny percentage of such fetuses might survive with the use of ultra sound, most, I suppose, with severe brain damage. To force such an existence on the nonviable fetus, or to protract its living death, is a matter of very serious ethical dispute.

Those who wrote this legislation are rightly concerned about the life and health of the fetus, so one wonders why they wish to sentence all of them to a slow death by strangulation rather than permitting them a mercifully rapid demise. Unless this bill is changed radically to a form that simply urges the obstetrician to use his or her best judgment in an attempt to salvage only those fetuses which can be salvaged, the nightmare of hundreds of isolettes filled with incubated, twitching, demented fetuses will become an actuality. All because of the physician's understandable desire to protect himself from criminal or professional liability.

The National Commission's report on Research on the Newborn Fetus came to the conclusion that so-called viability research on a fetus that had just been delivered was probably not acceptable. The Department of Health, Education and Welfare did not accept their recommendation and suggested that such research is acceptable if it is for the purpose of extending the life and health of the fetus. This opens up all kinds of Pandora's boxes of very unpleasant research that many of us involved in this field find quite unacceptable.

Aside from that dilemma there is also a practical aspect: financial implications. If there is a significant problem in California, that is, if a large number of viable fetuses are being summarily executed (which I think is clearly not the case), massive costs of medical care in a hopeless situation will be required. Unfortunately, the bill has a peculiar effect; it makes abortion very financially rewarding. The obstetrician can bill not only the mother, but also the fetus, and the hospital can also bill the fetus. I do not understand why the state of California wants to make the process of abortion so financially attractive.

The bill also provides another interesting problem in ethics. Most obstetricians dislike doing abortions; they do it as a necessary service for women with unwanted pregnancies. To force them into a position of further professional and criminal liability in the act of doing something they feel is for the good of their patient is something that we have to consider very carefully.

Finally, I would certainly caution the drafters of this legislation to be very certain that the language clearly

distinguishes between aborted fetuses and prematures; their descriptions of what is a fetus and what is a premature are very confused. It seems unlikely that the state wishes to offer ward status to all prematures.

I am afraid that California legislators will find themselves on a slippery slope of their own if they pursue this kind of legislation.

COMMENTARY

by LEROY WALTERS

There is an ambiguity in the concept of abortion. It may mean "the termination of fetal life," or it may mean "the separation of a fetus from a pregnant woman." In the early stages of pregnancy there is currently no feasible way to effect maternal-fetal separation without terminating the life of the fetus. However, as the gestational age of the fetus increases, particularly beyond the 20-week mark, the probability of its surviving induced abortion (or spontaneous premature delivery) also increases.

The likelihood of survival following induced abortion also depends on the method of abortion employed. The saline-injection technique raises the salt concentration in the amniotic fluid surrounding the fetus and usually results in the death of the fetus prior to its expulsion from the uterus. In contrast, the hysterotomy technique, which resembles a cesarean section, more frequently produces an infant which shows some signs of life. (This method is often used when a pregnant woman requests tubal sterilization at the time of abortion.) A third technique, the injection of prostaglandins, induces uterine contractions and effects the expulsion of the fetus in a process which, mechanically, simulates childbirth. In its effects on the fetus, this third method is intermediate between the other two: prostaglandins are less toxic to the fetus than concentrated saline solution, but the probability of live delivery following the injection of prostaglandins is probably not as great as following a hysterotomy.

Few reliable statistics exist concerning the frequency of live delivery and infant survival following induced abortion. New York State, where a liberalized abortion law went into effect in July 1970, has compiled the most complete data. In upstate New York between July 1970 and December 1972 there were 38 reported live deliveries following induced abortion. Of these, 27 followed 15,671 abortions by saline injection (live-delivery ratio: 1.7 per 1,000), and 9 followed 1,064 hysterotomies (live-delivery ratio: 8.5 per 1,000). Seven of the infants delivered with signs of life expired within an hour of delivery, 19 between 1 and 4 hours, and 10 between 4 and 24 hours. Two infants lived more than 24 hours: 1 expired at 27 hours and 5 minutes, the other survived without evident damage and was discharged into the mother's care (George Stroh and Alan R. Hinman, *American Journal of Obstetrics and Gynecology*, 125 (9): 83-90 (September 1, 1976).

Less complete data are available for upstate New York in 1973 and 1974. During 1973 there were 7 live deliveries and 1 survival following 5,751 abortions by saline injection or hysterotomy (live-delivery ratio: 1.2 per 1,000). In 1974, 15 live deliveries and no survivals followed approximately 5,000 abortions by saline injection, hysterotomy, and the use of prostaglandins (Stroh and Hinman, *op. cit.*) The overall live-delivery ratio for 1974 was 3 per 1,000 abortions; however, the ratio for live delivery following prostaglandin-induced abortions was considerably higher, at least 22 per 1,000.

Somewhat more sketchy data are available from New York City for the first 18 months under the state's liberalized abortion law. Sixty-two live deliveries, including 2 long-term survivals, were reported following approximately 36,000 abortions by saline injection or hysterotomy (live-delivery ratio: 1.7 per 1,000) (Pakter and Nelson, *Mt. Sinai Journal of Medicine* 39(6): 542, November-December 1972).

These New York figures can be combined with recent statistics from the federal Center for Disease Control (CDC) in Atlanta to compute a tentative national estimate of fetal survival following induced abortion. On the basis of data from 17 states (CDC, *Abortion Surveillance 1974*), one can project that approximately 6.4 percent, or 49,000, of the nation's 763,000 reported abortions in 1974 were performed by means of saline injection. If the upstate New York live-delivery ratio of 1.7 per 1,000 for 1970-72 held for the nation as a whole in 1974, then the number of live deliveries following saline-injection abortions in 1974 was approximately 84, nationwide. Corresponding estimates for hysterotomies are 0.4 percent, 2,896 abortions, and 25 live deliveries. Only the most tentative projections can be made on the basis of early statistics concerning prostaglandin-induced abortion. If the initial upstate New York ratio of 22 live deliveries per 1,000 prostaglandin-induced abortions is extrapolated to the entire nation, then in 1974 one would have expected 87 live deliveries from 3,950 abortions using prostaglandins. In sum, if these figures and projections are reasonably accurate, it is likely that in 1974 approximately 196 infants were delivered alive after abortion by saline- or prostaglandin-induction or hysterotomy. Of these, as the aggregated data from upstate New York and New York City suggest, perhaps 6 or 7 survived to grow to maturity. In future years these annual nationwide figures may remain relatively constant if the trend toward earlier abortion is balanced by the increasing use of prostaglandins and lower mortality rates among premature infants in general.

As the foregoing statistics indicate, the California state legislature is confronting a problem which involves a small number of infants. Even a maximal treatment program would not be likely to overwhelm the health-care system. However, the small number of infants delivered alive following abortion may possess certain human or legal rights which the legislature ought to protect, especially since the members of this class cannot speak for themselves. What principled basis for policymaking can be suggested to the legislature?

Two types of situations can be distinguished, the postabortion and the preabortion situation. Postabortion, I propose that the legislature adopt a formal-equality principle: all newborn infants should be treated equally, without regard to the circumstances of their delivery. The basis for this equality principle is the notion that, subsequent to its disconnection from the mother, the infant possesses independent rights. Two cases will serve to illustrate how the equality principle might work in practice. First, consider the case of a healthy, 2.2-pound infant delivered alive at 24 weeks' gestational age following a hysterotomy. If a hospital's neonatal intensive care unit would normally attempt to save the life of a spontaneously delivered infant of the same health status, age, and weight, then the equality principle would require identical treatment for the hysterotomy survivor. At the opposite extreme, consider the case of a 1-pound, 20-week-old infant delivered alive but with probable brain damage following saline-induced abortion. The formal-equality principle does not specify precisely what treatment should be given to such an infant. It merely requires that this infant receive the same treatment as a similar, spontaneously delivered infant.

The proposed equality principle implicitly rejects two alternative approaches to the treatment of infants that survive abortion. On the one hand, the principle does not recommend compensatory, especially vigorous, or maximal treatment for the survivors of abortion. A simple equality of treatment is sufficient. On the other hand, the principle also implies that, if the mother or both parents request that the surviving infant be allowed to die, this request should be denied if it conflicts with the principle of equal treatment. The independent claims of the infant are thereby recognized.

The preabortion situation raises additional complexities for the legislature. Here the central question is: should the state establish any requirements concerning permissible abortion procedures in the interest of maximizing the probability of infant survival following abortion? Three types of cases can be envisioned, those in which the fetus is clearly viable, clearly previable, and possibly viable. The first type of case is partially covered by existing American law. According to *Roe* v. *Wade* a legislature may prohibit the abortion of a clearly viable fetus unless abortion is required to preserve the pregnant woman's life or health. But let us suppose that at seven and one-half months of pregnancy immediate termination is medically indicated. Let us suppose, further, that two alternative methods of delivery exist, one of which increases the chances of infant survival but entails higher risk to the pregnant woman, the other of which decreases both the risk to the woman and the probability of infant survival. In my view, the law should not require moral heroism of the pregnant woman in this case by asking her to place her own life at higher risk for the sake of the viable fetus, just as the law should not *require* parents to rescue their children from burning buildings. If the above example is changed, however, to pose a choice between two alternative methods of termination, one of which has a lower risk for *both* pregnant woman and fetus, then the legislature could appropriately decide that the rights of a clearly viable fetus are sufficiently strong to justify requiring use of the safer method (unless other medical contraindications exist).

If the fetus is clearly previable, legislative enactments concerning the method of abortion are meaningless, since there is, by definition, no possibility of affecting the postabortion survival probabilities of the fetus. However, if the fetus is possibly viable, that is, if it is estimated to be between 20 and 28 weeks' gestational age, then the choice of abortion method may in fact have a significant impact on its survival probabilities. As in the case of the clearly viable fetus, the legislature would probably not wish to require that a pregnant woman choose a method of abortion which is more dangerous to herself (for example, hysterotomy) merely to maximize the chance of fetal survival. However, if a method of abortion becomes available which demonstrably entails lower risk both to the pregnant woman and the fetus (possibly prostaglandins), then, assuming the general availability of the safer technique, the legislature might wish to require the use of that technique in abortions performed beyond the nineteenth week of gestation (except in cases where use of the technique is medically contraindicated). The dual justification for such a requirement would be the enhancement of maternal health and the protection of fetuses which may have already crossed the viability threshhold.

Thus, to return to the ambiguity noted at the beginning of this essay, there may be cases in which abortion means the separation of a fetus from a pregnant woman rather than the termination of fetal life. If a legislature can limit the amount of fetal damage caused by abortion without endangering the life or health of the pregnant woman, then in my view it should do so.

International Population Programs: Should They Change Local Values?

In a Latin American nation both the government-sponsored and the private Family Planning Association programs have a policy of dispensing contraceptives to all clients who seek them, regardless of age or marital status. Neither program inquires whether married women using the clinics have the consent of their husbands. Similarly, neither program questions the marital status of younger women seeking contraception.

These practices have generated heated criticism. Several cultural leaders have stated that dispensing contraceptives to unmarried women, especially to young girls, contributes to moral breakdown in the nation. In their view the free availability of contraceptives from the clinics is directly responsible for rising "moral looseness" and a breakdown of traditional controls on sexual promiscuity among the unmarried. Moreover, some observers charge that making contraceptives available to married women without the knowledge or consent of their husbands is, in that society, an open invitation to infidelity. Although they can cite no statistics, several of these commentators feel that there has in fact been a notable rise in adultery since the programs were initiated.

Spokesmen for both programs defend their policies on the grounds that it is their task to prevent unwanted births among both the married and the unmarried, and that they are not the moral policemen for the nation. The representatives of the FPA program also point out that the World Population Plan of Action states that individuals have the right to the means for determining the number of, and spacing of, their children.

To what extent is freedom of contraceptive choice and availability a higher priority value than local social or religious traditions and beliefs with respect to sexual behavior?

—Donald Warwick

COMMENTARY

by THOMAS W. MERRICK

To respond to the question of priority that is raised in this case, it is necessary to look more closely at the values which appear to be in conflict. The value of freedom of contraceptive choice need not threaten morals. However, the manner in which a family planning program provides the means to exercise this choice could be offensive to local social or religious beliefs. For example, a comic book sponsored with foreign aid funds in Central America used a humorous reference to the Virgin Mary to promote contraceptives and was highly offensive to religious traditions. Similarly, clever billboard advertisements for contraceptives in Jamaica could be viewed as promoting promiscuity, at least in social contexts other than Jamaica.

In this case, however, the local family planning officials do not appear to be guilty of gross insensitivity to local customs. The issue is a more subtle one, involving both factual and "belief" questions. The factual question is whether access to family planning is a cause of the kind of moral breakdown described in the case. The issue is clearer if we turn the question around and ask whether restricting access to family planning to married women who have the permission of their husbands would in fact reduce promiscuity and marital infidelity. It would, I believe, be very difficult to establish this statistically.

Further, I doubt that the offended cultural leaders would really want to test the factual hypothesis. What is at stake for them is not the factual question but rather an underlying belief: a view that the risk of pregnancy ought to be the sanction for premarital or extramarital sexual activity for the woman involved (not the man, obviously). The risk of pregnancy (and a possible unsafe abortion) is believed to be a lesser evil than that of punishment in the afterlife or disruption of a male-dominated social order.

As a "value" to be upheld, I think that the notion of pregnancy as a sanction for illicit sex is wrong, and suppose that responsible moral authorities would agree with me. The problem in this case is that the local cultural leaders do view it as a value to be defended; hence a value conflict does exist. As a demographer, I do not have an ethical principle at hand to resolve the conflict, but my common sense tells me that if I *were* involved, I would advise the local family planning officials to act on the principle that access to family planning is a fundamental right. I would also be inclined to advise them to educate women in the idea that pregnancy need not be a sanction for sexual activity. I say "inclined" because I am aware that in so doing I am recommending that my own view of what is right be promoted over what I consider a "wrong" local belief.

This question of conflict with "wrong" local beliefs is, to me, the central question in the case. Who, after all, should determine what is in the "best interest" of these women or their society? The "wrongness" of the belief seems fairly clear in this case, but even here, and far more surely in more complex cases, there is the risk of ethnocentrism in determining what is in other peoples' best interest.

On this point it is essential that those who intervene in fields like family planning, which are quite likely to impinge

on "local" values, base their decisions regarding what is in the best interest of potential clients on a careful and sensitive understanding of local values.

Further, the attempt to understand these values should not be aimed simply at finding ways to realign them in the direction of increased acceptance of family planning. Rather the understanding should be directed at increasing these clients' well-being, and including family planning among measures to achieve it when appropriate. My strong impression is that family planning agencies are so convinced that access to contraceptives is in the best interest of their clients that they view this intermediate step as a waste of effort. This attitude is lamentable because even if their goal is basically correct, there is a higher risk of insensitivity to local values in the implementation of programs. If there is a lesson in this case for American population assistance policy in the Third World, it is that attempts to understand how family planning and reproductive behavior relate to individual welfare are justified even if their main objective is not to increase acceptance of family planning.

COMMENTARY

by ARTHUR CAPLAN

In some ways the ethical question asked at the end of this case is not the most pertinent one raised by the case. The question of which values—freedom of contraceptive choice or social and religious traditions—ought be given moral priority is only a subset of a larger, more familiar, and perennially perplexing problem. Is one group of individuals ever morally justified in replacing the moral values of another group with different social, religious, economic, or cultural orientations?

Since the values espoused by one society may vary from those of another society, some commentators on the policies of international health organizations have argued that it is wrong to interfere with the prevalent value systems. An admirable desire to respect cultural diversity, combined with a real fear of cultural imperialism, has produced a kind of moral paralysis among some individuals concerned with population issues. Since almost any activity by powerful Western medical organizations will inevitably alter prevailing norms and customs in the poorer nations and among disadvantaged minorities, a simplistic belief in cultural and ethical relativism (the idea that all values are the observable end-products of a complex of social, cultural and traditional variables and, thus, that one value is as good as another) quickly leads to a view that no activity encouraging population measures among these groups is morally defensible.

The desire to respect other cultures and the fear of imposing one's own values have a solid basis in present-day practices and historical fact. Attempts to promote Western-style medicine among societies whose medical problems arise from fundamental economic and political inequalities, and who have neither the need nor the hope of implementing high-technology medicine, have had disastrous consequences in many instances. Moreover, the basic inequalities in economic and political power between donors and recipients have sometimes led to the institution of unworkable, unwieldy, and even coercive programs of medical intervention upon persons who are too poor, too weak, too sick, or too desperate to protest.

Despite the practical realities presented by an attempt to respect cultural and value diversity, an unexamined commitment to ethical pluralism will not suffice as a moral maxim to guide population personnel behavior or organizational policy. The fact that individuals express divergent beliefs concerning values is not a sufficient reason to suppose that all opinions deserve equal weight, or that rational consensus is impossible.

This case provides an exemplary instance of the need to overcome a blind adherence to crude ethical relativism. If the distribution of contraceptives and information concerning birth control will alter the prevailing value norms of the society, can the agency morally justify its population control program? Any intervention into a sensitive area such as sexual behavior will prove disruptive to some degree; surely the agency has a duty to help the recipients anticipate and cope with such changes. However, disruption to prevailing values in itself is not a sound ethical reason against intervention.

Cultural values are not written in stone, especially when adherence to them may be based not on rational choice but upon ignorance, fear, myth, superstition, and compulsion. One key prerequisite for the defense of a moral value or standard is that it be based on a reasonably informed decision concerning its adequacy. If, as seems true in this case, the women of the society accept the prevailing standards of sexual conduct only because they fear pregnancy or are ignorant of the existence of birth control techniques, then the agency can argue morally that the women have a right to the information and technology which is requisite to making an informed choice concerning their sexual behavior. It is not always clear what information would be reasonable for a rational decision about a value question. But in this case family planning information is clearly relevant and the persistence of existing cultural values is suspect. Values that are maintained in a society through ignorance, fear, uninformed choice, and government fiat are not the best candidates for acceptance as moral values.

The line between reasonable intervention and aid and dictatorial coercion and imperialism is a thin one that has been crossed many times. But this fact does not obliterate the distinction. Cultural values that are in danger of collapse at the first sign of a relevant fact are hardly the stuff of which respect for cultural diversity and an appreciation of the richness of human variability are made.

Can the Fetus be an Organ Farm?

Mr. R, a twenty-eight-year-old engineer, has been on dialysis for three years, and is growing desperate because of the restrictions it places on his life. He can not work regularly because of the amount of time he has to spend in a dialysis center, and he feels weak and is suffering from many of the debilitating side effects of the treatment.

Mr. R has already investigated the possibility of obtaining a transplant. However, he had been adopted as an infant and does not know his natural family. In addition, tests show that he has a rare tissue type that makes it highly unlikely that a suitable cadaver kidney can be found.

Mr. R's physical and mental state continue to deteriorate and his wife suggests a solution to the transplant surgeon. She will, she says, become pregnant, and after five or six months, have an abortion. The kidneys from the fetus could then be transplanted in her husband.

The surgeon knows that technically such a transplant could be performed, and that the graft would probably not be rejected. He also knows that Mr. R has threatened to commit suicide if he has to remain on dialysis for an indefinite period.

Should he agree to transplant the kidneys of a deliberately conceived and aborted fetus?

COMMENTARY

by MARY ANNE WARREN

I would argue that if the relevant factors were only those described, then the surgeon ought to agree to the woman's plan to provide her husband with the kidneys of a fetus conceived for that purpose, and aborted at five or six months. I say "if" because I want to consider the morality of the action apart from any of the legal, professional, or personal complications that might arise if such a plan were actually carried out in today's world.

Even more than the typical abortion case, this case forces us to focus on the moral status of the (five- or six-month old) fetus, that is, on whether or not it should be considered a human being with a full-fledged right to life. For none of the more plausible arguments intended to show that abortion is morally permissible even if the fetus has the same right to life as an adult human being apply in this case: it is not a matter of self-defense on the woman's part, nor an exercise of her right to retain control of her body by refusing to submit to an unwanted pregnancy. Unless, therefore, one supposes that mere biological parenthood confers the right to kill one's offspring, at any age, one must conclude that if a fetus of this age is a human being with full moral rights, then the woman's proposal is tantamount to murder. On the other hand, if a fetus does not have a significant right to life, then the plan raises no serious moral problem, and provided that the operation has a good chance of saving her husband's life without seriously endangering hers, it should certainly be performed.

It is clear that if we are to make a reasoned judgment about the moral status of fetuses, and of nonhuman animals, alien life forms, intelligent machines, and other problematic entities, we must develop a criterion for the possession of moral rights that is species-neutral. That is, it will not do to make "genetic humanity" (mere genetic affiliation to the human species) either a necessary or a sufficient condition for the possession of full moral rights. To make it necessary is to beg the question against all nonhuman entities, even those which may prove to have intellects and sensibilities comparable or superior to our own; while to make it sufficient is to beg the question against abortion, particularly in a case like this one.

My candidate for a species-neutral criterion for the possession of full moral rights is what I call *personhood*. A person, to speak very roughly, is an entity that has the (actual, not merely potential) capacity for consciousness, complex and sophisticated perception, rationality, self-awareness, and self-motivated behavior. Such entities have rights by virtue of the fact that they have definite, preconceptualized preferences with respect to their own present and future states; they have desires, hopes, plans, and fears. Above all, they normally desire to go on living, or at least not to be killed in a way not of their own choosing. This is why killing people against their will is intrinsically bad, and in most cases morally wrong.

But fetuses, one might say, as yet have no will; they do not desire life, or anything else, any more than trees or amoebas do. Neither the mere *potential* to become a person, nor preconscious organic existence, not even a degree of sentience unaccompanied by the other aspects of personhood, can generate a right to life comparable to that of a person. Hence I think that there can be no serious moral objection to killing a fetus, an entity far below the threshold of personhood, in order to save the life of an adult human being.

I realize, of course, that most people will resist such a conclusion. Fetuses, especially those as old as five or six months, elicit our sympathy, and tempt us to endow them with moral rights, not only because they are potential people, but because they look disconcertingly like people; their physical features are recognizably human. But this sympathy is misplaced, unless there is a good deal more conscious activity in the fetal "mind" than we have any reason to suspect. While a fetus of five or six months may, perhaps, possess some flickering of sensation, or some capacity to feel pain, this is equally true and probably even more true of creatures like fish or insects, which few would doubt the propriety of killing in order to save human lives. In such cases, a proper respect for the right to life requires that it not be respected where it does not exist.

COMMENTARY

by DANIEL C. MAGUIRE

One of the most neglected ways to resolve an apparently irresolvable ethical dilemma is to ask: are there viable alternatives to that which is proposed? In this case, there is one alternative that seems to transform the dilemma of Mr. and Mrs. R making the intentional abortion for a transplantable kidney morally out of order. The alternative is: allow the baby to be born, and then see whether its tissue type is a suitable match. Since the mother's genes enter into the baby's genetic endowment, it is possible that the kidney will be incompatible with the father's rare type.

If the match is good and if the baby has two kidneys, one could be removed and given to the father. The greater maturity of the organ would likely enhance the prospects for successful transplant. Allowing the baby to be born changes the *what* of the case significantly, making the transplant proposal medically and morally more promising. The mother's plan to conceive a baby who might or might not have the right tissue type and to terminate the life of the fetus in any event is not the same case as bearing a baby who might, among other things, be a suitable donor for its father.

There are many reasons for having a baby, and, of course, the baby makes its own sweet case for living when it arrives. But, having a baby as a potential donor does not appear either evil or frivolous. And, medically, a born baby seems to have more realistic credentials as a donor. Even if the baby were not the right tissue type, its birth might possibly give Mr. R more zest for life helping him to bear his terrible affliction.

But suppose Mr. and Mrs. R insist that they do not want to have a baby, they only want to have a kidney. In reply I would point out the difficulty of having one without the other. More technically, I would say that they do indeed want a baby, but as a means not as an end. This is not self-evidently immoral.

In addition to these points against the abortion, I confess an extreme uneasiness in contemplating the very idea of the uterus as an organ farm or the fetus as an organ bank. Maybe my uneasiness is simply a shrinking before the unaccustomed, a horror of the new, or weakness of the masculine mind in the face of a tragic but moral option. Maybe the death of the fetus makes sense in a world where laying down one's life for a friend is the supreme moral achievement. The death of the fetus might be more easily entertained since it is preconscious, and not in the same human situation as a fully personalized adult.

On the other hand, my uneasiness may be the yield of moral intelligence. Ethics begins in awe and moves on to articulation, argument, and debate. Even in the midst of debate, the mind of the moralist should be attentive to the awe that is its foundation. In this case, my uneasiness, plus the facts and alternatives, conspire to make me very certain in offering a negative moral judgment on the proposed abortion.

One question remains: what right have we to presume the permission of the baby in donating its kidney to its father? Shouldn't the autonomy and privacy of the baby be protected until it grows to adulthood and can consent to such a dramatic donation?

A baby is not born outside the pale of human solidarity. It is a horrid individualism that sees the baby born into a "state of nature" with no debts or beneficent relationships to the social body until it "consents" to participate in the social contract. A baby is not an alien untouchable or a mere candidate for human communal existence. "Person" is a relative term and even baby-persons are intrinsically related to other persons.

Relationship to the other and the capacity for sharing are present before we are aware of them, since they relate to our elementary humanity and not just to our subsequent maturity and volition. Part of the awesome grandeur of parental care is the right and duty to interpret sensitively what a baby's humanity entails. And it may entail the surrender of a paired organ when that surrender is "a gift of life." The inability to permit this has its roots in an isolationist-individualist anthropology that ostracizes the baby from genuine humanness under guise of protecting its nonadult status.

Notice that the issue here cannot be discussed merely at the level of consent—whether personal or proxy. It involves the foundation upon which one's entire ethics is based.

COMMENTARY

by CAROL LEVINE

The conception and birth of a wanted child have always been among humanity's most powerful affirmations of life and its intrinsic value. When a pregnancy is unwanted, and abortion is contemplated, it is usually because of some serious reason —contraceptive failure, rape or incest, severe medical problems in the mother, probable genetic defects in the offspring, or economic deprivation. In these case the rights and interests of the already existing person must be weighed against those of the fetus. Abortion in such cases need not be condemned; neither, of course, should it be celebrated.

The scheme proposed in this case study, however—planned conception followed by planned abortion for the sole purpose of producing a body organ—is a perversion of both acts. Creating life in order to destroy it mocks both religious and humanistic concepts of the value of an individual. Manipulating the procreative process in this way transforms it from a natural and positive act to a callous and calculating one that transcends the permissible limits of human interference.

And one need not be opposed to abortion in all cases to be opposed to it in this one. The fetus is not an adult or even an infant; neither is it a chicken or a carrot. As what I would consider a potential person, it has at the very least the right to be treated with respect and dignity, and not as a source of spare parts for another's body. In carrying out this scheme, Mrs. R would not only be using her unborn child solely as a means and not as an end, but she would also be permitting herself to be used in the same unethical way.

But would this violation of the moral imperatives of valuing life and treating persons as ends and not means be acceptable because of another, more compelling principle—saving the life of another human being? There may be situations in which it is the highest form of altruism to

sacrifice one's life to save another's, but that is not at issue here. It is harder to imagine situations in which one person may be allowed to sacrifice the life of another, even potential, person, to save a third, but even that is not at issue.

Consider the facts. Mr. R is not dying —he is only threatening to kill himself. Two medically accepted therapies are available for his kidney disease. He has tried dialysis, and finds it too restricting. Now he wants a transplant, and no near relatives or suitable cadaver organs are available. But even if the aborted fetus's kidney were available, success is by no means guaranteed. With present medical knowledge, such a transplantation is technically feasible, but it is not certain that the kidney tissue will match or that if it does, the graft will take over his failed kidney function. Rejection rates for kidneys from related donors are much lower than for cadaver organs; even so, a third fail within five years.

Transplantation itself involves a not inconsiderable risk of death. Even the successfully transplanted patient faces the frequently serious medical and psychological effects of continuous immunosuppressive drug therapy. It is quite likely that the best Mr. R could hope for is a few years' respite from dialysis, and then what? Another conception? Another abortion? Another transplant?

Mr. R finds dialysis intolerable, but thousands of other patients like him have learned to accept it. For some it is even the treatment of choice: it is more predictable, safer, and less damaging to the body over the long run than repeated transplants.

But Mr. R does not feel his life on dialysis is worth living, even though he has a supportive wife to share his difficulties. In a desperate attempt to give her husband the reason to live that she alone apparently cannot provide, Mrs. R is willing to use her body to produce the kidney he wants. Can her offer be considered entirely voluntary, or must it inevitably be suffused with the guilt and bitterness she must feel knowing that her husband values her not as a marriage partner, or as the mother of his child, but as an organ incubator? Threats of suicide can be very persuasive, but they are at the same time coercive.

I believe that the transplant surgeon should refuse to participate in the abortion scheme. Instead, he should try to help Mr. R to understand and adjust to the practical alternatives. Some psychiatric counseling seems in order for Mr. R as well as marriage counseling for the couple. Adding the burden of a morally unacceptable act to a serious medical problem and a troubled marital relationship would only deepen their despair.

Risk Taking and a Minor Birth Defect

Linda Robinson, a twenty-eight-year-old actress, is eight weeks pregnant. Her five-year marriage to a magazine photographer has been strained by their dual career demands and their indecision over whether to have a child. During one particularly difficult period, when her husband had just gone away on assignment and Mrs. Robinson failed to get a part in a play, she became very anxious and started taking about 20 mg of Valium every day. She continued taking the drug in that dosage for about a month, although once she took 35 mg. Then she discovered that she was pregnant and stopped taking the drug. Her obstetrician referred her to a genetic counseling clinic to evaluate the potential effects of the drug on her child.

Dr. Andrews, the genetic counselor, told Mrs. Robinson that the only reported effect of Valium on pregnancy was a three- to fourfold increase of cleft lip and/or palate. Since the normal risk is only one in a thousand, the risk to her baby was only three to four in a thousand, in Dr. Andrews's words, "very small compared to other possible birth defects." Furthermore, he pointed out, cleft lip or palate can be corrected quite easily surgically. He found nothing else in her history (or in as much of her husband's as she could tell him) that would indicate she was at particular risk for bearing a child with any other kind of birth defect.

Mrs. Robinson seemed somewhat upset by the thought of a birth defect that might mar her child's appearance, but said she wanted time to think about this information. She confided to Dr. Andrews that she had just been offered a part in a television series and that her husband would be returning from his trip that week. She would, she said, discuss the situation with him.

The following week Mrs. Robinson returned for a follow-up visit. She said that the risk of a cleft palate was too high, and that she would have an abortion. Dr. Andrews felt that she was not being completely open about her reasons, and that she was ambivalent about her decision. She hinted, but did not directly ask for his advice.

What should the genetic counselor's role be? Should it be to explore the other possible reasons for her decision—her career, her marriage, her concern with physical appearance? Should it be to restate more forcefully the information that the risk was small and the defect, if it occurred, remediable? Or should it be to accept the client's decision on her own terms, on the grounds that she had been given full information and was free to make any choice she liked?

COMMENTARY

by ROBERT REDMON

The questions raised by this case and by countless others that occur in genetic clinics around the world can be viewed as a debate between those who believe in "directive" counseling—emphasizing a particular decision that the counselor believes is preferable—and those who state that the role of the counselor is simply to supply information, so that their patients/clients can apply their own values to make an appropriate judgment, the "nondirective" model. Indeed those who hold the nondirective view do so as a matter of moral principle, since to do otherwise seems to them to violate client autonomy or to impose value structures that may be foreign to the individual.

The active, directive view is often chosen by genetic counselors who view the individual as a patient, not a client. They believe that they must assume some responsibility for the outcome of their contacts with the patient, and thus some responsibility for the patient's behavior and decisions. As one genetic counselor put it, "It is neither right nor desirable to evade a personal commitment when it is desired and might be of help. It is in the nature of the doctor-patient relationship that the doctor assumes at least some responsibility for the patient, influences his decisions and, therefore, must answer for them as well" (W.F.F. Vogel, *Genetic Counseling*. Springer-Verlag, 1969, p. 97).

The nondirective view toward genetic counseling, on the other hand, is expressed in a 1975 statement from the Ad Hoc Committee on Genetic Counseling. The Committee held that the task of counseling is to "communicate" with "clients" (not patients) so that they "comprehend the medical facts," "understand the options," are able to "choose the course of action which seems appropriate to them in view of their risk and their family goals" and can "make the best possible adjustment to the disorder." The task is not to influence the client, but simply to inform her. To do otherwise would be to infringe upon the client's autonomy.

The assumption underlying this directive/nondirective debate is that informing someone or communicating with her is a matter of implanting some thought, imprint, ideas, or whatever, in the subject's mind. How she assimilates, judges, and reacts to the information is a separate matter. The directive counselor says that he has not finished his job until the patient reacts in a certain way, and the nondirective one claims that getting the right ideas in the client's mind is enough.

Informing someone is not simply saying something. It is saying something that has a desired effect. And the effect is not merely in the mind. If A says to B, "It is raining," and B does not rush outside to put up the top of his beloved sports car, then A has not *informed* B that it is raining (B did not hear A, B does not understand English, etc.). To inform someone, to communicate, is to say something that results in actions (or the disposition to act) of a certain sort, which includes being able to cite reasons for those actions.

To return to Mrs. Robinson and Dr. Andrews: Dr. Andrews seems to have failed to inform Mrs. Robinson because Mrs. Robinson's actions are not appropriate. The abortion decision is not the problem. The problem is that she has stated the wrong reason for the abortion. If she did not want to burden a shaky marriage with a

baby or if she did not want to interrupt her career at this point or if the fear of other defects was cited as a reason, this would have let Dr. Andrews know that he had succeeded in giving information. But citing fear of a 3/1000 risk (of a minor defect, at that) and ignoring a 6/100 risk (the statistical average) of other problems is irrational and shows a failure to comprehend.

The statement by the Ad Hoc Committee on the goal of counseling must be supplemented by an adequate view as to what constitutes communication, information giving, and so on. The counselor's values must govern his judgment as to whether information has been given. He must decide which effects are more serious (a value judgment) as well as the probabilities of their occurrence. And he must determine if the response is appropriate to these facts, to be sure the client has been informed. If the nondirective approach is best, then the counselor must allow for a wide range of responses. But a wide range does not include every response. It is Dr. Andrew's responsibility to explore the reasons behind Mrs. Robinson's decision; to try to elicit a rational response.

Which brings up my final point: the counselor must be quite clear about his own values. In order to tell if someone is responding irrationally, we must have criteria for rationality. At least two of the major components of rationality are (1) an appropriate set of beliefs about reality, including probabilities and reasoning processes and (2) an appropriate value structure which, for example, places a higher value on the life of a human than of a mouse, or which places a greater dysvalue on Down syndrome than on a cleft palate. We all require such structures in order to communicate, and the counselor must be aware of his own and those of his clients.

COMMENTARY

by JOYCE BERMEL

Twenty-eight. Married five years. A difficult time in a woman's life. Mrs. Robinson is going through the anxieties of many young women today, caught between her desires for a career and the disturbing realization that if she is going to have a family she had better start soon.

In her case the decision is even harder than it might be for, say, a woman who is a lawyer or a doctor with an established practice. Her career has its ups and downs. It obviously won't pay for a housekeeper. Once the baby is born she may have to cut back on going to auditions, and that in turn could mean fewer jobs and less money.

Her husband, who's wrapped up in his own career, probably won't be much help. He's away on assignment often. It was during one of his trips, while her own career was going poorly, that Mrs. Robinson started taking Valium. Her physician might have done better to refer her to a marriage counselor or a psychologist than to a genetic counselor.

But Dr. Andrews was called in. He thought the information he gave Mrs. Robinson would reassure her. The only birth defect known to be associated with Valium is a three- to fourfold increase in cleft lip or palate, which is "corrected quite easily surgically." The likelihood of the baby having that or any other birth defect is, in his estimation, small. To a genetic counselor that is splendid news. Compared with many of the clients Dr. Andrews sees—women who run the risk of having babies born with Down syndrome or spina bifida—Mrs. Robinson is wonderfully lucky. Her decision to have an abortion must seem irrational. It goes against the best scientific information.

But what does a baby represent to Mrs. Robinson? Perhaps she sees it as a chance to hold her strained marriage together, a mistake many women persist in. Perhaps she hopes her husband will stay closer to home once he is a father, and take photos of their beautiful child. As an actress, she may put a premium on looks and so may her photographer husband. A baby born with a physical blemish does not fit into the picture. And a child who requires surgery may heap more problems on this already rocky marriage. What, then, should the genetic counselor do?

First, he must recognize that, whatever her reasons, Mrs. Robinson has a legal right to an abortion. It does not matter whether Dr. Andrews regards appearance as sufficient cause; it does not matter whether other reasons are at work. Mrs. Robinson does not have to justify her decision to anyone. With that firmly in mind, Dr. Andrews has several options.

He can simply quote the statistical data and consider his job done. But a mechanical presentation of facts is a poor approach under any circumstances. It adds ammunition to the frequent charge that medicine has become depersonalized, and it ignores the counselor's role as advisor. Many genetic counselors see value-neutrality as a mark of professionalism, but carried to extremes it makes a mockery of the consulting process.

Or, Dr. Andrews can press Mrs. Robinson to make one decision or the other, based on medical information. In this instance, since he believes that the risk of the defect is small and the condition is remediable, he will probably advise her not to abort. But, given the complex circumstances of Mrs. Robinson's life, this advice might not be doing her—or the unwanted baby—a service.

There is another path that Dr. Andrews can take to help Mrs. Robinson clarify her own thinking. He can raise the question of whether Mrs. Robinson is using the scientific data as a smokescreen. He can suggest that other matters seem to be troubling her. Since he has not been trained as a psychologist or psychiatrist he may find himself on slippery territory. And, of course, he may be wrong. Still, he owes it to Mrs. Robinson—and to the baby in formation—to at least raise the possibility, and to suggest that Mrs. Robinson discuss her doubts with him, her husband, or her physician.

It bothers me that Mr. Robinson did not join his wife on the follow-up visit to Dr. Andrews. The counselor should have suggested—even requested—that they appear together to consult about a matter of such importance to them both. While the ultimate decision about whether to have the baby is Mrs. Robinson's, obviously her husband's feelings influence her, or she would not have deferred her decision until his return. She needs to know how her husband feels about bringing up this or any other child, and a three-way consultation might be a good place to start.

Abortion is not an action to undertake lightly. But then neither is motherhood. Mrs. Robinson made her decision to abort shortly after she had been offered a television role. The tradeoff may appear ridiculous to some, but the choice between having a career and caring for children has not yet been resolved in our society.

Sterilizing the Retarded Child

A retarded eleven-year-old girl from the city of Sheffield, England, had been booked to enter a hospital on May 4, 1975, for a sterilization operation. The girl, known as "D," suffers from Sotos Syndrome—also called cerebral giganticism—an unusual group of congenital abnormalities including epilepsy. Characteristics of the disease include large hands, feet, and skull; poor coordination; and endocrine problems of unknown etiology. Intelligence ranges from normal to severe retardation, with most mildly retarded. ("D" had a normal intelligence range, a fair academic standard, and the understanding of a nine- to nine-and-a-half-year-old.)

While authorities in the genetics of Sotos Syndrome are uncertain about its inheritability, they believe that it is not one disease but a heterogeneous group of disorders, and that it may be either a recessive trait or a new dominant mutation. Most cases of Sotos Syndrome have been sporadic, occurring equally in both sexes. Those afflicted do not seem to have a higher incidence of relatives affected than does the normal population, and the risk of genetic transmission is not known. There have been reports, however, of its occurrence among first cousins, identical twins, and between father and son.

"D's" father died in 1971, leaving the mother to raise the girl and two other daughters in very difficult circumstances. The mother, a part-time cleaner, is very hard-working, sincere, and devoted. The girl sleeps with her mother in one bed; their two-bedroom house has no toilet; and they live under conditions described as appalling.

In 1973 "D" was transferred to a school specializing in children's behavioral problems, a move reported to be a success. Her progress in education and behavior was evident. But by the time "D" reached puberty at the age of ten the mother had grown concerned, fearing her daughter might be seduced and have an abnormal baby, for which she would then have to care. She stated: "I don't think my daughter will ever be responsible enough to bring up a family. I don't think she will improve enough to look after children." However, "D" had not yet shown any interest in the opposite sex, and her opportunities for promiscuity were virtually nonexistent since her mother was always at her side.

Dr. Ronald Gordon, a consultant pediatrician at Sheffield Northern General Hospital who had taken an interest in the family, said that there was a risk that any child borne by "D" would be abnormal and that the girl's epilepsy might cause her to harm a child. He thought that she would always remain so substantially handicapped that she would be unable to care for herself or any children she might have. He maintained that his recommendation to operate was based on his clinical judgment; furthermore, he claimed that he and the gynecologist, Dr. Sheila Duncan, should be the sole judges of whether surgery should be performed, provided that there was parental consent. Dr. Gordon also asked the mother, who consented to the sterilization, to discuss the operation with her daughter.

Mrs. Margaret Dubberley, an educational psychologist at the school the girl attended, strongly opposed the operation and brought legal proceedings aimed at having the girl made a ward of the court. The headmaster at the girl's school believed it was unrealistic to be dogmatic about "D's" future, a view supported by some medical evidence. Mrs. Dubberly was further supported by the National Council for Civil Liberties and by a movement in the House of Commons opposing the operation.

COMMENTARY

by LEROY WALTERS

Before we examine the normative issues in "D's" case, it will be useful to analyze precisely what kind of sterilization is being proposed on her behalf. Since there is no evidence to indicate that the sterilization of "D" is medically required for the diagnosis or treatment of an existing illness or injury, the proposed sterilization can be categorized as *nontherapeutic*. A more complex question is the voluntariness of the proposed procedure. The surgery envisioned is clearly not compulsory, or involuntary, in the sense of being performed against the expressed wishes of the daughter. However, "D" is legally a minor and is probably not mentally competent to provide voluntary consent to the surgery on her own behalf. Perhaps a third category is required —nonvoluntary sterilization, or sterilization in the absence of the prospective sterilizee's consent or refusal. The proposed sterilization in "D's" case would seem to correspond most closely to this third category; that is, if performed, the sterilization would be nonvoluntary and would be authorized by the substituted judgment of the mother and the two physicians.

Under what conditions can nontherapeutic, nonvoluntary sterilization be morally justified? I would like to suggest three formal requirements which should be applied to this and similar cases. First, there should be *just cause*, or a sufficiently weighty reason, for the proposed sterilization. A just cause is required because sterilization in the absence of consent constitutes a significant invasion of the body and a rather massive intrusion into the sphere of reproductive privacy that has recently been recognized by Anglo-American law. The second requirement is that steriliza-

tion should be a *last resort*, since it is generally irreversible and since equally effective, reversible contraceptive techniques are available—for example, the pill. The third formal requirement is *due process*, or an adequate procedure for representing the interests and protecting the rights of all parties concerned.

The proposed sterilization of "D" satisfies none of these formal requirements. First, there is no just cause for the sterilization of "D." It is not clear whether sterilization was recommended by the mother and the pediatrician primarily for the benefit of "D" herself, for the benefit of her mother and sisters, or for the benefit of a child which might potentially be conceived and born to "D." (Another logical possibility, not mentioned in this case, would be sterilization for the benefit of society as a whole.) However, no convincing arguments are presented to support any of these possible justifications. The evidence concerning the probability of "D's" producing handicapped children is inconclusive at best. In addition, the prognosis for "D's" own intellectual development is uncertain. It is at least possible that with the aid of continued special education she will one day be able to make informed decisions concerning her reproductive capacities.

Second, the proposed sterilization of "D" is clearly not a last resort. In the case report there is no evidence to indicate that reversible contraceptive techniques were either considered or tried. Until such alternatives have been demonstrated to be infeasible, consideration of an irreversible surgical procedure is premature.

Third, the proposal to sterilize "D" also fails to satisfy the due process requirement. Quite possibly the physicians and the mother based their decision primarily on the best interest of the child, as they perceived that interest. However, the "clinical judgment" of the physicians extended far beyond the bounds of the medically indicated. Even the mother, whose response in very difficult circumstances is understandable, did not sufficiently consider the rights of her child. In cases where the performance of an irreversible, nontherapeutic procedure on a child is contemplated, due process seems to require either the appointment of a guardian for the child or formal approval by an independent review committee. This at least seems to be the view of the U.S. Department of Health, Education and Welfare (as expressed in the sterilization restrictions published in the *Federal Register* February 6, 1974) and the British Department of Health and Social Security, as outlined in a discussion paper, "Sterilization of Children under 16 Years of Age" (cited in the *British Medical Journal*, November 8, 1975, p. 356).

It is easy to forget that the momentary act of nonvoluntary sterilization has lifetime consequences for the person undergoing the procedure. A sociological study in the December 1962 *Eugenics Quarterly* by G. Sabagh and R. B. Edgerton reported that, of forty retarded persons who had been sterilized prior to their release from the institution, many understood "the meaning and implications of sterilization" and 68 percent "disapproved of the sterilization procedure which they had undergone."

In sum, the proposed sterilization of "D" in this case fails to fulfill the requirements of just cause, last resort, and due process. The preferable alternative would be to employ nonpermanent contraceptive techniques as necessary, in the hope that one day "D" will attain sufficient intellectual maturity to make her own reproductive decisions.

This case occurred in England, where the courts acted to prevent the sterilization of a mildly retarded eleven-year-old girl. What are the precedents in the United States? The complex legal issues involve questions of valid consent, substituted consent, and the dual incompetence of retarded minors due to age and mental disability.

According to a survey on "Capacity, Competence, Consent" in the *Columbia Human Rights Law Review* (Fall-Winter, 1974-75), the general rule of common law is that parental consent suffices to authorize medical treatment for a minor child because treatment is assumed to be potentially beneficial to the child. The dual incompetence of retarded children complicates the problem of establishing "benefit." The authors found no case where a parent's informed consent to sterilization of a retarded minor had been challenged. However, in a 1974 case (*In re M.K.R.*, 515 S.W. 2d 467) the Missouri Supreme Court ruled that, in the absence of statutory authority, the juvenile court lacked jurisdiction to authorize sterilization of a mentally retarded child whose mother had petitioned the court for approval. And in *In re Anderson*, (1974), a Wisconsin court denied a father's petition to authorize the sterilization of his nineteen-year-old (majority age) daughter. In regard to court-ordered substituted consent, Judge Gerhard Gesell, in *Relf* v. *Weinberger*, 372 F. Supp. 1196 (1974), ruled against authorizing federal funds for sterilization procedures unless the personal consent of the incompetent was secured. He criticized proposed DHEW regulations concerning sterilization, in part because mentally deficient minors are incapable of providing voluntary consent.

In the twenty-one states where statutory provisions do exist, the laws require or permit involuntary sterilization of institutionalized mental incompetents; of these states, nine have statutes that deal with noninstitutionalized persons as well. Most of the laws are based on eugenic grounds. Guidelines to protect the adequacy of consent have not yet been established.

COMMENTARY

by WILLARD GAYLIN

When analyzed in terms of the specific data presented in this case, a court decision to prevent irreversible surgery seems reasonable enough; and that is, in fact, what took place. The child is, after all, still young; the nature of the mental impairment is still unclear; the degree of retardation (and possible maturation that can be expected) has yet to be defined. There will be a time for a reevaluation when the facts of her destiny become clearer.

The actual response the court's decision elicited, however, was not what one would expect for a prudential compromise, but more like that which is accorded a victory of the forces of good over those of evil. The applause in Britain and elsewhere was as unanimous and hearty as though Tinkerbell's life depended on it. One suspects that it was not the eleven-year-old girl and her future that was being judged, but a cliché. For years sterilization of the mentally retarded has been an issue fraught with emotion. The ominous implications of genetic engineering, cast in the shadow of the recent Nazi past, make the problem too easy by evoking an instinctive and intuitive response to the connotation of the words employed rather than their explicit meaning. Here was an issue that managed to unite educational psychologists, the medical establishment, the civil libertarians, and the House of Commons on one side —with only the unfortunate girl's mother in opposition. Any moral issue in biomedicine these days that commands such unanimity warrants a reexamination.

What is needed is some understanding of the value of sterilization in the mentally retarded. An automatic negative response is not warranted; and the reason is precisely the one sometimes relied upon by opponents of sterilization—that we now recognize the mentally retarded as a broad spectrum of individuals who, while limited in their capacity for certain functions of the healthy mature adult, are not limited in all.

One of the great disadvantages of IQ as the measurement of retardation is that it forces us to see the retarded of all ages as children. We describe them as "having the mentality of a six-year-old." No mentally retarded individual has the mentality of a six-, eight-, twelve- or fourteen-year-old. A six-year-old is a learner par excellence, with unbounded intellectual curiosity, and a potential for mastery of new material that a thirty-six-year-old would envy. He is, however, immature, childish, and incapable of making the decisions which his profound intelligence might imply. A thirty-six-year-old with severe retardation to a point where he can neither read, write, count, tell time, nor follow street directions, can still be a mature adult in a host of ways beyond the capacity of the six-year-old. The price we make the retarded pay for their incapacity in one area is the sacrifice of capacity in certain other areas which could be compensatory if allowed to develop.

Because we cast mentally retarded adults as children we are appalled, for example, at the thought of their having a sexual or even a social life. Deprived of the joy and privilege of parenthood, for which they may have no capacity, they are punished further by being denied the privilege and pleasure of affection, tenderness, romance, and sexual contact for which they may indeed have a capacity.

A mentally retarded individual ought not be given the responsibility of raising a child, and indeed a mentally retarded woman could be terrified of the changes in her body which pregnancy would produce. Sterilization could allow for the kind of innovation in social living lacking at most facilities for the mentally retarded. There is no reason why community living, even a family-type living, that involved affection, tenderness, and sexuality could not be a fundamental part of their lives and partly compensate for their lack of ordinary intellectual pleasures. Instead we punitively add one deprivation onto the other.

Sterilization is, after all, simply a word. There is nothing in the procedure itself that is innately evil. We allow sterilization when its benefits for the individual outweigh its costs. It is a legitimate procedure, offensive to some for religious reasons but not to others. In this matter society ought to respect the individual conscience and the individual value.

When, as with the retarded, the concepts necessary for intelligent decision making are beyond a person's intellectual grasp, we would be wise to leave the power of the delegated autonomy in the hands of the family. If that is abused all sorts of legal mechanisms exist for rectification. What state right warrants intrusion into the decision making? If it is established (first by the family, then if there is suspicion of abuse, by courts), that the mental retardation is of a degree that precludes the role of parent, the young woman will be deprived only of the "privilege" of conception and, presumably, abortion. She will gain, however, new freedoms, and her parents will gain peace of mind.

The incursion into the powers of the family by the state, here as in other places, is often cast in the noble language of rights. What is really at issue in many arguments about "fetal rights," "infant rights," and so on is in reality the relocation of delegated autonomy and power from one institution—the family—to another—the state. Too often the kind of government intervention we have been seeing in these difficult cases, where right and wrong are too finely balanced for comfort or confidence in any decision, represents arrogance rather than compassion. It is unseemly and demeans the state, for more often than not the state is acting not *in loco parentis* but simply as Nosey Parker.

If "D's" incapacities to be a mother are still evidenced when she is fifteen years of age, she, through the agents of her care, that is, her family, ought to have the right to exercise the privilege of sterilization.

The Hospital's Duty and Rape Victims

Dr. Maria DeCicco is Chief of Emergency Care at St. Mary's Hospital in a large southern city. She has been put in a difficult situation by the passage of a state Rape Victim's Emergency Treatment Act and recent amendments to the municipal code mandating certain services for rape victims. The state law requires hospitals to collect evidence for the police. Kits are provided for this purpose at no expense to the hospital. Hospitals must also provide, with the patient's consent, minimum treatment including an emergency room examination, counseling, and advice about possible infection or pregnancy.

The city's municipal code specifies the treatment in greater detail and creates the real problem for Dr. DeCicco. The treatment required by the code includes, with the patient's consent, medication against conception and venereal disease. Dr. DeCicco has, as a matter of conscience, always tried to use her medical skills to preserve life. She feels that abortion is morally wrong and went to great lengths to find a position where she could practice medicine without having to provide such services. That is why she joined the staff of St. Mary's. Their policy against abortion was firm and well known. Patients in the community would normally not come to St. Mary's if they were considering abortion.

The new municipal code appears to require that she and her staff provide not only emergency medical services, which she is happy to do, but also medical intervention to interrupt any pregnancy that may result. Although the cells to be destroyed by the "morning after" pill are newly fertilized, to her, their destruction is the moral equivalent of an abortion.

Dr. DeCicco recognizes that the ethical issues are a matter of substantial controversy. She is not seeking to impose moral judgments on anyone else. She only wants to practice medicine as her conscience dictates, yet the new state and municipal mandates seem to require her to participate in what she believes is a morally objectionable practice in order to protect the rights of the rape victim.

She has talked with the administrator of the hospital. He strongly agrees that the hospital should not be forced to provide medical intervention to stop any potential pregnancy. He proposes that they ask the municipal authorities for an exemption from the requirement if they would pledge to provide counseling to rape victims coming to their emergency room including information to the effect that the hospital does not provide any services that could lead to an interruption of any possible pregnancy. This would leave the patient free to seek such service elsewhere.

Dr. DeCicco is not satisfied with the suggestion because she objects to being put in a position where she would have to counsel patients or refer patients to services where the end result was possibly going to be an interruption of a pregnancy. She is beginning to feel that she can no longer practice what she considers responsible medicine without violating the law. Should society provide some escape for Dr. DeCicco? If not, should she violate a law that she objects to so strongly?

COMMENTARY

by J. DAVID BLEICH

Much of the current debate concerning abortion practices is clouded by a failure to distinguish between the legal and moral issues involved. *Roe* v. *Wade*, the Supreme Court decision governing abortion statutes, established a "right to privacy" insofar as performance of abortions is concerned and serves to prevent governmental authorities from prohibiting such procedures. There is absolutely nothing in that decision that *requires* a physician to perform an abortion. The physician retains freedom of conscience and freedom of religious practice either to perform or not to perform an abortion. The physician, no less than the mother, enjoys a constitutional "right to privacy." Any municipal ordinance *mandating* that the physician destroy a fetus upon the demand of the mother would probably be held unconstitutional by the courts.

A municipal ordinance requiring that a rape victim be informed of the medical options available to her and be provided with information concerning availability of abortion services is an entirely different matter both legally and morally. Legally, failure to provide such information, even in the absence of a legal requirement to do so, may constitute malpractice. As such, the rape victim may have a cause of action to recover damages from the physician. That, however, is a civil matter upon which the legality of the municipal ordinance has no bearing. Morally there is a conflict between the patient's moral autonomy, which can be exercised only if she has an informed awareness of the viable options available to her, and the physician's conscientious objection to providing information which, from his or her moral vantage point, can be used only in an immoral manner.

There may be a way to escape from between the horns of this dilemma. Although, by virtue of the tenets of her faith, Dr. DeCicco cannot refer patients to another medical institution for interruption of pregnancy she may well be able to provide information with regard to the options available. While I am certainly not qualified to pass upon matters of canon law, it would appear that merely providing information constitutes no more than "remote material assistance" to an immoral act which, from the vantage point of Catholic morality, is justified when "serious cause" exists for doing so. Loss of one's profession is recognized as constituting not merely "serious cause" but "grave cause."

Moreover, the prospect of St. Mary's Hospital being forced to close its emergency care department—with all that such a step would imply in terms of availability of treatment in life-threatening situa-

tions—is certainly "proportionate reason" for rendering what is no more than "remote material assistance." Whether civil authorities have a moral (or legal) right to require even remote assistance to an act perceived as immoral by some citizens is an entirely different question.

More significantly, the ethical problem posed in this case study may be more apparent than real. Assuredly, if such is her conviction, the physician, as a moral agent, is obligated not only to refrain from destroying the fetus but also to urge her patient not to seek an abortion elsewhere. Surely, any intelligent person living in our society should consider it not only likely but also highly probable that the rape victim will leave the emergency room of St. Mary's and proceed to seek aid in terminating her pregnancy elsewhere. Under such circumstances, it would be no more than proper for the physician to present the moral case mitigating against such a course of action. In the very act of offering moral counsel—which the physician should feel morally compelled to do even in the absence of a legal requirement—the physician will have provided the legally required information.

But let us assume that there is no way for the physician to provide this information without violating her moral principles. Such convictions deserve the respect of both society and the law. Any attempt to compel compliance with a law perceived by a responsible segment of society to be inconsistent with the moral code to which it subscribes, regardless of the goal which such a law seeks to further, is an attack upon morality itself. Violation of conscience very quickly leads to a breakdown of conscience—and surely there are few goals, if any, whose benefits outweigh the societal benefits of preservation of a sense of moral conscience.

Instead of tampering with Dr. DeCicco's conscience the municipal authorities would be better advised to embark upon a public information program designed to provide all citizens with pertinent information regarding available health care facilities and the policies adhered to by the various medical institutions in the community. They would also do well to provide information in an objective, dispassionate manner with regard to the moral perspective upon which the policies of such institutions are grounded. Indeed, it would be wise—and fair—to require St. Mary's Hospital to post a notice in a conspicuous place in the emergency room which would inform patients of the hospital's policy with regard to services leading to termination of pregnancy.

Should a conflict between law and morality remain, there is no question that Dr. DeCicco's duty to conscience is such that she cannot act in a manner which the law prescribes. The only options available to her are civil disobedience or abandonment of the practice of medicine. Under the circumstances I believe disobedience of the law would be morally defensible. One must remember that, for Dr. DeCicco, feticide is indistinguishable from homicide. Who would be unsympathetic to disobedience of a legal requirement to counsel homicide?

Indeed, the constitutionality of an ordinance requiring a physician to provide such information is open to question. Enforcement of such a requirement under these circumstances would require the demonstration of a "compelling state interest." It is not at all certain that such an interest exists. I would therefore urge Dr. DeCicco to pursue the matter in the courts. It may readily be argued that she has a moral obligation to do so. Historically, the courts have been extremely reluctant to permit the law to tamper with religious or moral convictions. May they have the good judicial sense to refuse to do so in this case as well.

COMMENTARY

by CAROL A. TAUER

Dr. DeCicco believes that the law requires her to participate in a morally objectionable practice in order to protect the rights of the rape victim. The rape victim's rights have already been gravely violated by an invasion of her body about which she had no choice. After the rape, it is essential that her right to choose be restored to her, that she be given the opportunity to decide how she will deal with the actual and potential consequences of the rape and with the weighty moral issues involved.

Beyond emergency care, the rape victim's primary right at this time is self-determination. But in order to exercise this right, she needs information about the options that are open to her. This information is standard scientific and medical knowledge. It is well-known to those who are educated and advantaged in our society. By providing the information to all rape victims, a doctor or hospital is simply equalizing opportunity, the opportunity of all rape victims to make an informed choice.

Dr. DeCicco is not being asked to convince the victim to take the "morning-after" pill. In providing information, she is in the position of a teacher who must clearly outline the scientific aspects of biomedical procedures that raise ethical questions. It is appropriate for either the teacher or the doctor to express her own moral or value judgment. But she cannot make this judgment for others. And in depriving the rape victim of information, the doctor is attempting to prevent the victim from making a particular choice, thus depriving her of moral freedom.

Although the hospital and doctor ought to provide the information the law requires, if they have serious moral objections to prescribing the "morning-after" pill, this should not be required of them. The hospital has a clearly stated position against abortion, and it regards intervention in the period between conception and implantation to be morally equivalent to abortion. In taking this position, the hospital has the support of the Ethical and Religious Directives for Catholic Health Facilities issued by the National Conference of Catholic Bishops. It should therefore be possible for the hospital to obtain an exemption from the specific requirement of providing the "morning-after" pill.

If Dr. DeCicco cannot bring herself to give the information and counseling required by the law and approved by the administrator, she should ask to be removed from her present position and assigned elsewhere in the hospital.

Beyond these immediate decisions, however, both Dr. DeCicco and the administrator should recognize that they may be wrong in their moral evaluation of the "morning-after" pill. For at least ten years, numerous Catholic theologians have been questioning the inviolability of the embryo during the first two or three weeks after fertilization. They respect it as nascent human life, but believe that it does not require all the protections given to an individual human being. For a serious reason, for example, the prevention of pregnancy

due to rape, the early embryo could be deprived of the environment it would need for continued development. Dr. DeCicco and the administrator have the obligation to become familiar with this theological literature in order to inform their own moral judgments.

Another point for them to consider is the phrase "morally equivalent." In what sense is use of the "morning-after" pill morally equivalent to a sixth-month abortion? We may say that the energy crisis is the moral equivalent of war, and that chain smoking is the moral equivalent of suicide. Such expressions are at least partly figurative, and to take them literally leads to moral confusion. Catholic adolescents of my generation experienced this confusion on being taught that any deliberate sexual arousal was morally equivalent to premarital sexual intercourse. Sorting actions into large, all-encompassing categories is not a good way of making moral judgments. *Is* taking the "morning-after" pill in case of rape, truly as great an evil as obtaining an abortion at six months? To say *yes* seems to indicate a rigid adherence to set rules and categories without regard for the morally relevant distinction that obtains.

If Dr. DeCicco and the hospital recognize that there is a moral distinction, that even if both acts are evil, one is a lesser evil than the other, then they ought to be interested in preventing the greater evil. Almost any woman who becomes pregnant after a rape will at least consider the possibility of having an abortion. Unless she is sexually ignorant, she will be thinking about the possibility of pregnancy and abortion when she is in the hospital emergency room. Dr. DeCicco claims that she does not want to be part of any practice where the end result might be an abortion. But in not allowing the patient to choose the "morning-after" pill, the doctor is limiting the patient's options so that the end result may well be a direct abortion. If the patient does not want to go through with a pregnancy, the doctor ought to counsel the least evil way of terminating pregnancy, and the more immediate the intervention, the better: physically, psychologically, and morally.

2

Patient-Physician Relationships

The Homosexual Husband and Physician Confidentiality

David, the oldest of three children, was the son of a well-to-do manufacturer. David's father valued physical prowess and athletic accomplishments, areas in which David showed little interest. When David was twelve or thirteen years old, conflicts with his father resulted in almost nightly arguments. It was evident that David's father had become concerned about David's mannerisms and considered them to be effeminate.

David's schoolwork deteriorated considerably and he became withdrawn. His father decided to send him to a military school, but he remained there for only six months. By this time, David had told his parents that he was a homosexual, had engaged in, and was engaging in homosexual practices. He came home and completed his high school studies, but did not go on to college and continued to live at home.

He was treated for gonorrhea, asthma, and infectious hepatitis. At the age of twenty-one, to gain exemption from the draft, his physician attested to the fact that he was a homosexual.

Five years later, Joan visited her family physician for a premarital serological exam. The physician was the same physician who had treated David. She was twenty-four years old and had been under this physician's care since the age of fourteen. A close and warm relationship had developed between the physician and Joan's family, and it was normal, then, for the physician to ask about her fiancé. When he did, he learned that she was about to marry David. She had known him only briefly, but well enough, she felt, to be certain about her choice. Nothing more was said at the time.

David and Joan were married shortly thereafter and lived together for a period of six months. The marriage was annulled on the basis of nonconsummation. David told Joan that he was homosexually oriented, and she learned as well that not only did they share a physician but also that the physician was aware of David's homosexuality. She subsequently suffered a depression as a result of this experience and was angry that her physician had remained silent about David. She felt that she could have been spared this horrible episode in her life—that it was her physician's duty to inform her. His failure to do so was an act of negligence resulting in deep emotional scars.

To whom did the physician owe primary allegiance? Do the interests of one patient prevail over the requirements of confidentiality surrounding another's case?

—Harvey Kuschner

COMMENTARY

by DANIEL CALLAHAN

Why is there a general rule of confidentiality? That seems to be the first question to ask before looking at the details of a case like this. I believe the rule has three purposes. The first is to establish a context that will elicit from the patient maximum disclosure of the patient's condition, a major requirement for effective diagnosis. The second is to recognize, in a working way, that patient's lives are not disconnected from their bodies, that both the causes and cures of illness have a personal and social context, and that effective diagnosis and therapy require going beyond the boundaries of the merely physical. The third purpose is the general one of maximizing patient trust and thus strengthening the bond between physician and patient. Seen in this way, the rule of confidentiality is readily justifiable.

But should it be a flat rule, admitting of no exceptions? Clearly, our society thinks not, for it has established a number of circumstances which require physicians to report their patient's condition to public authorities, e.g., dangerous communicable diseases and gunshot wounds. These are reasonable exceptions, which simply recognize that some otherwise private conditions have significant public implications. It is not just the welfare of one patient which is at stake in those situations, but the welfare of other individuals as well.

Most significantly, the conditions under which confidentiality must be violated are matters of public law and knowledge. Hence, disclosures will not represent any arbitrary imposition or expression of the physician's personal values. They are public rules, binding upon all, and simply because of that fact they are not taken to endanger the general goal of patient-physician trust (and there is no evidence they have done so).

In the case before us, there are no mandated social rules for making an exception. And yet clearly the circumstance was one in which not just the welfare of one person (David) was at stake, but also that of another (Joan). Implicitly at least, those conditions were present which in other—but publicly specified—circumstances, the welfare of one individual is allowed to be overridden by consideration for the welfare of others. So in one sense it might be said that the physician could have broken confidentiality and done so on the grounds of a non-arbitrary and otherwise justifiable principle.

Yet I would argue that the critical issue in this case is not that the physician could have brought an otherwise legitimate moral principle to bear, but that, in this particular type of case, there is no known *public* moral rule about the breaking of confidence. David would have had no complaint had he appeared with a gunshot wound; that is a well-known circumstance for violating confidentiality. No such reasoning applies in the case of homosexuality, and David could well have felt that the physician was inventing his own set of moral rules and imposing them on him.

Are we then to conclude that the rule of confidentiality should have been honored in this circumstance? I am afraid so, however disturbing the implications of honoring it were for Joan's future life. If there is to be a rule of confidentiality, then it must be a clear and flat rule, not admitting of ambiguity and unclear exceptions, much less the devising of personal and idiosyncratic interpretations. David's trust would have been betrayed, the physician would have been imposing his own private meaning on the moral rule and we the public, though minutely, would have been harmed by the breaking, in our midst, of a general principle meant to protect us.

Am I happy with such a rigid outcome? Well, not really. As a member of the wiggling and squirming school of moral reasoning, let me propose two possible solutions. The first is that there are conditions under which I would allow a physician to break confidence. If this physician had told David that his moral scruples were such that he felt he must break confidence, that he would make it openly known to others that he was doing so, and that he would be willing to take the social punishment which might result (a malpractice suit, for instance), then I think the physician would have acted in an honorable way. The point is that there can be moral reasons for breaking even the most rigid of rules, and rigid because they are so socially important. But the test of the moral rectitude when a rule is broken is that it can be done in the daylight and that the rule-breaker be prepared to pay a social penalty. It is the breaking of rules in the dark, dodging the personal consequences, which is the real threat to patient-physician trust.

The other solution is a more dangerous one, but perhaps justifiable in this case, given the special intimacy of the physician with both David and Joan. He could have asked David for permission to break confidence, and attempted by persuasion to get David to agree. Or he could have tried to persuade David to tell Joan himself. He could have gone back to Joan and asked her just how well she knew David, talking all the while in a general way about the importance of couples knowing as much as possible about each other before marriage—the vaguest of hints, that is, that she should want to know more about David. Or, finally, he could have talked with them independently of each other. This policy of deliberate but directed ambiguity involves walking a dangerous line, but I think it would have been justifiable in this case.

COMMENTARY

by ERIC J. CASSELL

We can no longer draw a simple distinction between moral and medical problems, at least in an internist's office. What we used to call the "medical facts" and the "personal facts" are indistinguishable. In this case, for example, David had gonorrhea and in-

fectious hepatitis, both diseases of increased prevalence among male homosexuals; he had problems in school and job instability, also common among this group. But more important, both the medical and personal problems are in the realm of the moral, because the problems here had to do with the welfare of two individuals.

What really creates the dilemma in this case is that the physician had cared for both patients for a long time, and had an equally longstanding obligation to both. I believe that he ought to have explored all possibilities that might have led to disclosure but without, finally, breaking confidentiality.

At the very least the physician had an obligation to say to David, "Have you told Joan that you are a homosexual? If you haven't, you really should." Having done this, he might be acquitted of his obligation in much the same way a physician might ask a man who is getting married and whose family has a history of genetic disease whether the bride knew about it.

Second, I believe that the physician had an obligation to discuss her sexuality with Joan prior to the marriage, in order to get some sense of knowledge, problems, expectations, and needs. Perhaps Joan knew full well that David was a homosexual. Indeed, that knowledge may have been one of the conditions of the marriage and of its eventual failure. Just as David expressed his hostility to his father through his school and other problems, it is possible that Joan may have been acting similarly in marrying a homosexual.

In common with every other physician, I suppose, I have been stunned by finding out during my sixteen years in practice that the world and the way people manage to live in it is not at all like I thought it was when I started out. A similar case arose in my own practice. I have known a couple for fourteen years, and they are both my patients, although the wife was not originally my patient. The husband has had a series of intriguing, original, and tangled affairs. He has also had several episodes of gonorrhea, syphilis, and assorted other diseases and disasters. The family is still intact, with one child; from my point of view, it's a rather odd family, but this couple has managed to make an accommodation to this most tangled maze.

I tell couples that marriage consists of three individuals: the man, the woman, and the marriage, and that each deserves privacy and consideration. I don't like husbands or wives automatically accompanying each other into the doctor's office.

I feel the same way about parents and children. I tell parents of adolescents that it is an absolute rule in my office that a child is allowed to see me without my necessarily telling the parent what the visit was about (without the child's permission), unless I believe the child's life is in danger. If the parents can't live with this, then I don't want to be the child's physician. I have a sense that in the long run wisdom is best served by this absolute rule of confidentiality. It does keep physicians from deciding—on the basis of their own limited knowledge—what indeed is in a patient's best interest in complex matters.

COMMENTARY

by ROBERT M. VEATCH

One principle shared by physicians and lay people is that, at least in uncomplicated cases, the physician should convey to the patient any medically relevant information that would be potentially meaningful or useful in medical decision-making. The physician's Hippocratic ethic instructs him that he should do what he thinks will benefit his patient. Lay people form similar conclusions from other systems of ethics, ones that focus on principles of autonomy and honesty.

The tradition of physician ethics on confidentiality is not at all clear. The Hippocratic Oath, marvelous in its ambiguity, says that the physician ought to keep secret things he learns in his practice that ought not to be "spread abroad." Which things those are is not specified. The World Medical Association's twentieth-century version of the Hippocratic Oath states simplistically that the physician will keep confidences entrusted in him.

On the other hand, the American Medical Association takes a quite different approach. Its principle of ethics says that the physician ought not to disclose things learned in confidence except in three cases: when disclosure is required by law, when it is in the patient's interest, or when it is in the interests of other people. The AMA insists on the physician's duty to persons other than the patient from whom the relevant information has been learned, thus taking a much more social course. But it opens the door for a wide range of disclosures.

Nowhere does traditional physician ethics say anything about resolving conflicts between duties to two patients whose interests may not be the same and whose values and interests may differ from the physician's.

By the time the physician has reached the dilemma in the case of this man and woman, there may simply be no morally acceptable resolution. If the problem of potential conflict had been faced earlier, then several solutions might have been acceptable. Had the physician as an individual, or physicians as a profession, or society as a whole adopted a policy that physicians will not disclose any information obtained in confidence unless, say, life is imminently in danger, then this problem would not have arisen. Alternatively, the AMA rule that confidence can be broken when it is in the interests of others to do so could have been adopted, also eliminating the moral conflict. If there is no good solution to the problem as it evolved, is there anything the physician can do to make the best of an impossible situation. I think there is.

Assuming that the physician is convinced that the information would be important to the woman, he could explain his perception of the situation to her future spouse, determine whether she does know about the homosexuality, and try to convince him of the importance of telling her. If he agrees, the physician's problem disappears. If he does not, the physician has three options.

First, he could continue in both physician-patient relationships without disclosing. This seems to me to be the least acceptable option, a basic violation of the implicit contract based on trust and confidence.

Second, he could disclose anyway, after explaining to the man that he has a moral obligation to do so. (Although I am convinced that such a case might arise, I am not convinced that this situation fits this description.)

Third, he could withdraw from one or both of the relationships. He might claim that his practice was so busy that he had to transfer one or both to a colleague—a blatantly deceitful explanation. He could say openly that he had to break the relationship because of information received in confidence. That would provoke so much curiosity that it might lead to violation of the confidence. He could say vaguely that conditions in his practice were such that he had to transfer one or both to colleagues. As unsatisfactory as this solution is, I believe that it may be the best moral compromise available.

In transferring the woman to another physician, he no longer has a duty to do what would benefit her as his patient. That satisfies the Hippocratic rules, but somehow to me it is still morally very unsatisfying. In fact, from my standpoint as a nonphysician, the duty to disclose is strong even if the person who may benefit from the disclosure is no longer the physician's patient. Nevertheless, breaking the relationship is preferable to continuing in a relationship that must be based on trust without disclosing.

This case shows how important it is to know clearly what the ethical ground rules are at the beginning of a relationship. I prefer openness and disclosure, even if privacies must occasionally be violated. If patients know in advance that the physician may be forced by conscience to break confidences in certain limited situations, I do not think a patient ought to object to such disclosures.

Choosing a Therapy When Doctors Disagree

A 32-year-old man was admitted to the hospital with a recurrent skin tumor. Several years earlier he had noticed that a mole, which had been present for at least 5 years, was beginning to change in color and bleed. He visited his private physician who recommended its removal and referred him to a nearby surgeon. After excision, pathologic examination showed that the skin lesion was a malignant tumor. This led to the surgical removal of a larger portion of adjacent skin and of lymph nodes draining the area. Just before the current hospital admission a lump appeared a considerable distance away from the initial site of disease. When the patient's physician examined him in his office he considered this to be evidence of the return of tumor and arranged for his entry into the hospital's surgical ward.

A series of consultations have now been arranged, both by the surgeon and by the intern and resident staff. These are intended to clarify the medical issues of the case, not only in the patient's own interests but as an exercise needed for the training of young physicians.

A group of internists has arrived and at this moment is considering the facts in this case and management alternatives. There are two approaches possible to the existing medical dilemma. Cure is unlikely once the disease has escaped regional confines defined as the lymphatic drainage area of the original tumor. The new nodule may be surgically excised, but there is a very high likelihood that another one will appear elsewhere within a short time. On the other hand, an experimental immunological approach may be used which involves the injection of material directly into the malignant tissue in an effort to evoke an immune response that may have long-lasting benefit. A suitable period of discussion is closed by a statement from the senior immunologist who says "In my opinion, while the outlook is grim either way, at least the experimental approach gives the patient a new chance not offered by conventional therapy. I would therefore favor its use. However, since this case is on the surgical service, I have no doubt that the malignant tissues will be excised. Our recommendation, however, should be recorded."

COMMENTARY

by YASHAR HIRSHAUT

THE ETHICAL ISSUE raised by this case is whether the patient should be involved in the consideration of alternative therapies for his disease. Involving him appears to me undesirable for a number of reasons.

Lack of expertise—The selection of appropriate therapy for any condition depends on a full understanding of disease processes and the influence of alternative therapeutic regimens on these. Differences of opinion regarding the proper treatment are usually based on each physician's assessment of the likelihood that any given therapy will be effective. In such evaluations experience with other patients having the same disease is important, as is knowledge of similar cases in the literature. The patient, lacking this information, is not in a position to choose intelligently between treatment options.

Fear—In order fully to assess the situation in the case described, the relative risk factors would have to be made clear to the patient. In a virtually hopeless situation more would be lost by the emotional consequences of his realization of impending disaster than would be gained from his satisfaction of having exercised a right to participate in the selection of one or another marginal therapy.

Perception—In facing the seriousness of his current health problem, the patient realizes that his entire ability to exist is being undermined. Therefore, the illness is not seen as an isolated manifestation, but is a matter which will have an impact on every aspect of his life. To ask for objective judgments under these circumstances is to request the impossible. Even the facts of a case are perceived more as nightmarish fantasies than acceptable elements of the true situation. Psychological defense mechanisms such as denial or depersonalization must come into play to preserve sanity. Rather than ethical it may be immoral to burden the patient at such a time with making a medical decision for which he is not qualified in any case.

Loss of Confidence—The patient comes to the physician as he does to his dentist, lawyer or accountant expecting expert guidance and advice. When the dentist fills his tooth he relies on the dentist's knowledge of proper procedure. A lawyer who argues legal points with his clients instead of with a judge or jury is hardly worth his fee. Similarly a physician should resolve medical issues in his own mind and then advise his patient on a course of action he thinks would produce the best results. To do otherwise risks the loss of the patient's confidence in his physician.

Patient Ambivalence—In instances where treatment may produce discomfort, such as nausea, vomiting or pain, the natural reaction of the patient is to try to avoid the procedure. The other day a woman in the hospital was offered a combination of two treatments, one of which was relatively benign, while the other was associated with quite unpleasant side effects. The patient argued vigorously against the second treatment and

claimed she would be satisfied with just one therapeutic modality at a time. Within a few hours, after consulting with a specialist, her physician came back and told her that he would proceed with the one approach. Instead of finding the patient reassured, he noticed she was frightened and even more agitated. On questioning, she indicated that the physician appeared to be relying on her own judgment and that since she was no expert this might be faulty. She feared, therefore, that by having spoken out she might have caused herself long-term injury. While this is usually not so, there may be instances when involving patients in therapeutic decision-making increases their ambivalence and may cause the abandonment of an otherwise important and worthwhile treatment.

COMMENTARY

by DAVID BLEICH

THIS CASE presents a wide array of ethical issues. Whether or not the patient should be informed of the nature and prognosis of his illness is certainly pertinent, but is hardly the most significant question in the case at hand. Attention should be focused upon a cluster of three basic ethical questions raised by this case.

The question of who should make the ultimate decision when a choice between alternate modes of therapy must be made is an obvious issue and one which must be faced. On the one hand, respect for principles of personal autonomy and freedom of choice would augur for giving the patient the opportunity to choose the treatment to be administered. On the other hand, the physician, who is better informed and has more understanding of the medical complexities, is in a position to make a more intelligent decision. Either side can be argued with a great deal of cogency. But, even were it to be granted that the decision is best left to the doctors, is it ethical that the patient not be informed that there *is* significant disagreement among the members of the medical team whom he has entrusted with his care? Should not the patient, or his family, be accorded the opportunity of further consultation?

It may well be the case that some patients are incapable of coping with situations requiring difficult decisions or would be devastated by the realization that the physician is himself in a quandry. Certainly, the existence of some such individuals does not justify monolithic treatment of all patients in this manner. Patients capable and desirous of making their own decisions should not be deprived of their right to do so simply because other patients lack the capacity for decision-making.

A second, and far more perplexing, issue presents itself in this particular case. The patient has not been fully informed (and this *does* present a problem with regard to the patient's "*informed* consent" to the proposed surgery). The decision has been made by the physician—but in a manner which appears to be entirely unconscionable. It is quite evident that the patient will undergo surgery simply because he has been admitted as a patient on a surgical service. Had the patient been admitted to a medical service, the decision, in all probability, would have been quite different. Should vagaries of what "bed" a patient happens to occupy be allowed to serve as the determining factor in choice of treatment?

It is not surprising that the immunologists, apparently unanimously, favor immunological treatment and that the surgeons, again unanimously, favor surgery. There is no doubt that that they are all "good men and true." Each however, is closest to his own specialty, is more thoroughly familiar with the treatment he is trained to provide, is a greater advocate of its efficacy and is more enthusiastic about its promise of success. This, in itself, is entirely as it should be. What is necessary is a way of choosing between competing claims and anticipations. The fact that the surgeons and immunologists have apparently communicated with each other only via the medium of written reports is somewhat disturbing. One wonders whether or not a dialogue between the two groups would not have been fruitful. Perhaps a meeting of minds would have emerged.

In this case, the patient occupies a surgical bed and hence the surgeons are in a position to implement their decision. What would happen in the (unlikely) case that the surgeons recommend immunology while the immunologists recommend surgery? Buriden's ass, equidistant between two piles of hay, bereft of the capacity for free choice, dies of hunger. Surely the patient should not be left in a no-man's land between the two services.

Assuming, *arguendo*, that the choice is to be made by physicians rather than by the patient, should not the decision be made by a third group of doctors who are literate and knowledgeable in both areas but whose fields of specialization are distinct from both surgery and immunology? This course of action may indeed be cumbersome and time-consuming. But such a third group of physicians would be objective and dispassionate and would be in a position to review the findings and reach a meaningful decision.

This case, however, presents us with a third, and perhaps more fundamental, issue. In this instance the claims advanced both by the surgeons and the immunologists are, in all likelihood, substantially correct. The ultimate decision, although predicated upon medical realia, is not at all medical in nature. The choice in this case is between two courses of therapy: surgery, which will almost certainly secure remission for a period of time but which, in all probability, will not lead to a cure; or immunology which, if successful, will effect a cure but which, if unsuccessful, will hasten the patient's death. Which option is to be chosen is not a medical decision but a value judgment. The decision either way involves a gamble. The patient is gambling the certainty of a short life span against the possibility of a longer life expectancy. This is a decision which more properly lies with the patient and his moral mentors.

Eavesdropping on a Medical Assault

Recently a middle-class suburban housewife accompanied a friend who had broken her ankle in a fall to the emergency room of their local hospital. In the patient area next to them, separated by a curtain, was a teen-age boy in football uniform. The nurse who took information about the friend's accident told them the boy had suffered a shoulder separation in practice.

A doctor and nurse were with the boy, who began to scream, "No! No! Stop! Can't you put me out?" Apparently they were attempting to set his shoulder. The remaining curtains around the boy were quickly pulled. The woman heard no response to the boy's question, only more screams of pain. Someone said, "Give him Demerol." The boy said again, "Can't you put me all the way out?" and several times again shouted "No, No!"

After the medical personnel left him the woman could hear him quietly crying. The friend asked him (through the curtain) how old he was. He said, "Sixteen." She asked, "Is no one with you?" He said, "No, no one was home." The woman asked if someone was trying to reach his parents. He said yes. She called his phone number from the phone in the waiting room but there was no answer.

She then told the boy that he could sue for assault if he was treated without his permission, that perhaps they had needed to move his arm while he was awake to be sure they got it in the right place, but in any case they should have explained what they were doing and have obtained his permission.

Soon a nurse took him away. While the woman waited for the results of her friend's x-rays, she saw the boy's football coaches in the lobby. She overheard one say, "He didn't take it very well, did he?" Shortly after the boy's mother arrived.

A day later the woman wondered to herself: "Did I have a responsibility to do something more, or should I have avoided meddling—and, do I still have some moral responsibility to act—to talk to his parents or to attempt to get the hospital administration to investigate emergency room procedures?"

COMMENTARY

by JAMES SMITH

In some ways, the most remarkable aspect of this case is that it should be a problem at all. Our protagonist is quite assertive. She intervenes by trying to call the boy's parents and by suggesting to him the possibility of legal action. Although I doubt that this is very helpful advice, either immediately or in the long run, it certainly indicates a high degree of social aggressiveness. Yet she is agonized by the question of whether she should speak to the hospital authorities!

Suppose that the setting were a school, and that Ms. X had observed a teacher apparently bullying a student over the student's protests. Even supposing she had not intervened immediately, wouldn't she have been in the principal's office the next day, and, failing there, in the superintendent's office, and, failing there, at the school board? And rightly so. That may need qualification; but the point is that her attitude toward the doctor and hospital is more reverent than her attitude toward the teacher and school. In this, I suspect she is at one with the rest of the population. It is difficult to produce grounds for this difference in attitude; causes, of course, come readily to mind.

The answer to the question of what she should do now doesn't seem to me very complicated. Given what she saw and her interpretation of it and given her present concern, she has all the reason she needs for speaking to the boy to hear his view in a calmer moment, to his parents and (if her concern remains) to the hospital administrator or the relevant committee of the hospital. If there is no policy on emergency room procedures with minors, the use of anesthesia, etc., there certainly ought to be and the general policy (if not the medical details) should be intelligible to the layperson.

In particular, a layperson should be able to recognize a *prima facie* violation of them, so that Ms. X could know whether she has grounds for a complaint to the committee overseeing emergency room procedure or to the hospital board. If there is no policy, that is also ground for complaint. How far should she go? There is no helpful general answer. We are all familiar with the complaint that takes up so much time and demands so much detail that, in terms of improving public service, it is self-defeating. But given the reverential attitude I have already mentioned, the best answer in this case is: continue until all doubts are resolved.

On the other hand, I think Ms. X's nonintervention in the emergency room procedure is probably right, on the facts we have. Even if her suspicions that not everything was right were justified, she might well have made things worse by delaying or complicating the actions of the physicians at the time. If the facts were different, however—if there seemed a threat of iatrogenic injury in addition to pain—the problem would be much trickier to resolve.

I have referred neither to obligations, nor their more august siblings, moral obligations, because I do not find references to them, or even the search for them, especially helpful in

most cases. It is only where there is a fairly well-defined role governed by some articulable rules that what we ought to do is determined by an obligation. For most of us, most of the time, and for Ms. X in this case, it is enough to discover where the weight of good reasons lies.

COMMENTARY

by MICHAEL D. BAYLES

Both the case and the moral question asked are, like most real situations, ambiguous. It is not clear that any battery or assault occurred. Parents frequently give written consent to schools to obtain needed medical treatment for injured children. While the boy did say, "Stop," and ask about alternative procedures, one need not interpret these comments as denial of consent. Such remarks by a seven-year-old would naturally be taken to be an expression of natural fear rather than a request not to be treated.

Another problem is whether a sixteen-year-old boy with a painful injury is competent to consent. If he is not, the physicians have an implied consent for rendering aid in emergency situations. Further, the question asked is not whether the woman who observed the incident has an *obligation* to do anything, but whether she has any *responsibility*. It could be claimed that it would be good for her to intervene but she does not have an obligation or duty to do so.

There is an important difference between an obligation or duty to rescue others in distress and a right to intervene in their behalf. This case is difficult because it involves what may be called "benevolent battery." If the bystander saw two men on the street attack a boy, she would certainly believe it was not ultimately for the boy's physical welfare. She would have not only a right but a moral duty to intervene. In this case, however, she may believe the battery will ultimately be for the boy's physical welfare. What she probably believes to be bad is the manner in which the treatment is given and not the treatment itself. In short, she recognizes the paternalistic motivation of the emergency room personnel and probably agrees with their assessment (or at least is not medically qualified to differ) but disapproves of the paternalism.

What should she have done that she did not do? Given her concern, at the time she should have asked the physicians whether they had consent for the treatment. That would not have made things worse. Since the physicians could have taken time to explain the procedures to the boy and why anesthetic was not used, they could also have paused long enough to tell her why they believed they had consent. Simply asking the question may have made them decide to wait for a parent to arrive. Had no satisfactory answer been forthcoming, then the woman would have had a duty to rescue the boy from a battery. At the least, she should have gone directly to the person in charge of the emergency room to complain. In short, when confronted with a possible battery, one morally ought to determine whether it is one, and if it is, try to prevent it.

Moreover, when the woman learned that the coaches were present, she could have discussed the matter with them. In any case, given the person's concern about what she witnessed, she certainly should have spoken to the mother when she arrived. A conversation then would have avoided the worry about contacting the parents now. Whether the matter should or need be taken up with hospital administrators cannot be decided until one has a reasonably accurate interpretation of what happened. The bystander's current moral puzzle essentially stems from not knowing enough background to evaluate morally what happened. Had she been more inquisitive at the time, her current puzzles would not exist. She now has concern without information, which is as morally futile as information without concern. This case basically illustrates the results of a failure to fulfill the duty to become informed.

Proxy Consent for a Medical Gamble

Norma Walker had worked as a secretary at a large medical group practice and had resigned when six months pregnant. Nine days after the baby was born she experienced severe headache, fever, and a mild reaction to light. The next day, Sunday, she met with her obstetrician in the hospital emergency room. He found no abnormalities and felt strongly that further evaluation by an internist was imperative.

Since Mrs. Walker did not know an internist, she and her husband, an auto mechanic, were worried about finding a physician who would come to the emergency room on a Sunday morning. Dr. Stanley, one of the physicians from the office where Mrs. Walker had formerly worked and whom they both knew personally, happened to be in the emergency room at the time, and Mr. Walker asked him to assume care of his wife. Her obstetrician agreed.

Dr. Stanley learned that the Walkers' two-year-old son had recently had viral meningitis, as had several other children and adults living near their home. When reached by phone, their pediatrician confirmed that two children had been proven by lumbar puncture to have aseptic meningitis and had been treated conservatively at home. During the interview the Walkers expressed anger about the impersonal and unpleasant way Mrs. Walker had been treated by hospital personnel in the labor and delivery suite a week earlier. Mr. Walker was especially bitter and was certain she would have had better care at home.

The results of laboratory tests showed that Mrs. Walker probably had a just-beginning viral meningitis (for which no specific treatment is necessary), but may have had a bacterial meningitis (a life-threatening illness requiring treatment with intravenous antibiotics).

The test findings were carefully explained to the Walkers. Dr. Stanley stated that because of the circumstances, the chances of Mrs. Walker having viral meningitis were very high. But the result of the spinal fluid test raised the possibility of bacterial meningitis. The physician argued that, if he or his wife were the patient, he would play it safe and go into the hospital for two days of intravenous antibiotics until the spinal fluid culture was complete.

Mrs. Walker felt too ill to think clearly—she would, she said, do whatever her husband decided. Mr. Walker was determined to be involved in the decision. He was clearly concerned for his wife, but wasn't sure whether "playing it safe" was the best course of action. He appreciated the personal favor of the physician who had agreed to undertake her care on short notice and had given a detailed explanation of the medical evaluation. However, her recent hospitalization had left a bad impression. Also the couple had no insurance. Was the small chance really much of a gamble? Mr. Walker needed time to think and went for a walk.

Upon returning, he announced his decision—to take the gamble. He would take his wife home, fully aware of the risks and of Dr. Stanley's discomfort with his decision. Who ought to have made the decision about treatment in this case? Was Mr. Walker's decision justifiable? —Dennis F. Saver

COMMENTARY

by RONALD A. CARSON

Hospital care is often brusque and inconsiderate, at times even unkind. Patients understandably recoil from such treatment and seek to avoid it. Patients also, increasingly, want to take part in determining the shape of their care. The sophisticated patient expects a full explanation of what ails him or her and wants to contribute to decisions made regarding the course of treatment. The unsophisticated, too, often want to know—not the detail, perhaps, and all the possible options, but certainly the odds and the risks. They too often, wish to say, and have taken into account, how much discomfort and what degree of suffering they are prepared to undergo for this or that outcome.

While sensitive physicians are trying to be responsive to these sorts of expectations, an important and useful distinction ought not to be sloughed over, namely, the distinction between treatment decisions and decisions about the course of treatment. Treatment decisions are medical decisions in the strict sense, decisions predicated on the special knowledge of the medically trained. Assembling relevant evidence, examining it, and interpreting it is the proper business of physicians and should be left to them. Acting on an interpretation of that evidence to treat a patient in distress is also the physician's responsibility. Difficulties arise in cases such as Mrs. Walker's not in diagnosis or treatment, but on the way from one to the other. It is at this point that the physician must consider the treatment options available and weigh their probable outcomes. It is at this juncture that competent adult patients rightfully become partners with their physicians in the decision-making process.

Course-of-treatment decisions are not medical decisions but life decisions. At issue are the physical, psychological, and social effects this or that treatment is likely to have on this particular patient and those nearest him or her. Gauging those effects does not require medical expertise but rather knowledge of the patient's circumstances "from the inside." Choices about the course a treatment should take (and, indeed, the choice between treatment and no treatment) are most appropriately made by those who stand to bear the consequences of the decision.

The decision required in this case is a medical one. This does not mean that the patient and her husband should be excluded from the discussion. But, knowing the consequences of bacterial meningitis, Dr. Stanley was right in recommending

hospitalization for prophylactic treatment until lab results conclusively ruled out a bacterial infection. He had to consider the possible effects of Mrs. Walker not receiving adequate care at home (antibiotics, administered intravenously) and of her being at home with what might turn out to be a contagious disease. True, the evidence for viral meningitis was all but overwhelming, but it was also circumstantial. The presence of those white cells caused Dr. Stanley to hesitate and recommend precautionary treatment.

It is clear that Mr. Walker considered the decision one he had to make (a course-of-treatment decision) and that the physician saw it as a treatment decision. What is not clear is the degree of forcefulness the physician used in recommending hospitalization. If the proper interpretation of symptoms and test results is what is at issue, the recommendation to hospitalize and initiate prophylactic therapy should be insisted upon by the physician. The Walkers may, in the face of that insistence, take it upon themselves to go home, but the physician will not have encouraged that decision by offering them a choice which is not theirs to make.

COMMENTARY

by HENRY ARANOW, JR.

I have conducted my medical practice on the assumption that competent adults have the right and the responsibility to make final decisions about their own medical care. They may, if they so desire, delegate this responsibility to another competent adult of their choosing.

The inflammation of the covering of the brain designated by the term "meningitis" is almost always accompanied by some inflammation of the adjacent brain substance. This latter, if of sufficient extent and degree, may cause disturbances in thinking. Some patients with meningitis are manifestly mentally incompetent to make a reasoned decision about their treatment options. The case description states, "Mrs. Walker felt too ill to think clearly—she would, she said, do whatever her husband decided." The portion of the history of the patient's illness given in the abstract is very scanty, nor are any of the details of the physical examination performed by Dr. Stanley included. The statement that her obstetrician found no abnormalities seems to refer to abnormalities of her reproductive system, since he felt that further evaluation by an internist was *imperative* [my emphasis]. Such information might have been of value in attempting to evaluate Mrs. Walker's mental competence.

When the decision of a person given the responsibility of making a therapeutic decision on behalf of another differs sharply from that recommended by the physician charged with the patient's care, I believe it is the duty of the physician to present to the patient himself or herself the considerations that led to the recommendations rejected by the patient's delegate. Under such circumstances, the mental competence of the patient is of utmost importance.

The case description leads me to believe that Dr. Stanley felt that Mrs. Walker was competent to delegate the decision-making responsibility to her husband. This competence means to me that, when Mr. Walker's decision differed so strikingly from his own, he should have re-presented his arguments to Mrs. Walker, explaining the bases of his professional recommendations, informing her of the risks inherent in the course chosen by her husband, persuading her to withdraw the delegation of decision-making authority from him, and deciding for herself to accept Dr. Stanley's advice.

In my view, the medical arguments for in-hospital treatment are overwhelming until the test results definitely exclude bacterial meningitis. Bacterial meningitis can be a fulminating illness in which a delay in therapy for even a few hours may lead to death or permanent disability. To permit the mother of two children, who has a central responsibility in their care and upbringing, to run such a risk because of her anger and that of her husband "about the impersonal and unpleasant way she had been treated by hospital personnel in the labor and delivery suite a week earlier" strikes me as, in the highest degree, unwise and irresponsible.

We are asked: "Was the small chance really much of a gamble?" My answer is that for such stakes, "It is an appalling one!"

The wisdom of any medical intervention may be evaluated by computing the cost/benefit ratio to the patient and, less importantly to her family and to society. With the possibility of the death or serious disability of a young mother in one pan of the balance, against two days of undesired and possibly unnecessary hospitalization in the other, the indicator bangs against the end of the scale in the direction of hospitalization and treatment.

It is clear that I do not believe Mr. Walker's decision was justifiable. The fact that Dr. Stanley was only "accidentally" involved in Mrs. Walker's care raises the possibility in my mind that he might have pushed his recommendations much harder with both the Walkers had he been their "regular" or "personal" physician.

COMMENTARY

by NANCY K. RHODEN

Competent adults can, in general, refuse medical treatment even when their refusal is unwise, ignorant, or life-threatening. Such situations are agonizing, but more agonizing, and much more complicated, are situations where third parties refuse treatment for others. In the case at hand, Mr. Walker is making a decision with potentially disastrous consequences for his wife's life and health.

Initially, at least, he has the right to make this decision, since his wife has delegated decision-making power to him. There should be a strong presumption in favor of a proxy's decision when he has recently, and competently, been authorized to decide by the patient herself. But this presumption should not be absolute. Any third-party decision-maker has an obligation to promote the patient's best interests and to make a decision which the patient could reasonably have made herself. Decisions by parents or court-appointed guardians which violate this duty can be challenged. Decisions by authorized proxies should be subject to similar scrutiny, to guard against unreasonable decisions or decisions based upon ulterior motives.

In this case, despite the couple's lack of insurance, the facts as presented suggest

that Mr. Walker acted from concern for his wife. Obviously, if his motives were suspect, Dr. Stanley should take further action. But the real problem here is not Mr. Walker's motive, but the reasonableness of his decision.

Given the facts at hand, is his decision justifiable? Such decisions can be evaluated in several rather disparate ways. They can be considered in purely medical terms—what is the probable diagnosis, what are the relevant risks of alternative courses of treatment, and so on? By these criteria, Mr. Walker's decision is probably unjustifiable. Competent physicians would likely agree as to the need for hospitalization here, at least for observation, because bacterial meningitis can very quickly become life-threatening.

Mr. Walker's decision, however, should not be evaluated solely on medical grounds. Individuals do not make personal treatment decisions in exactly the same way doctors do: rather, their decisions are necessarily, and properly, influenced by their personal values, needs and preferences. Though proxy decision-makers are, correctly, given less leeway to be idiosyncratic, their decisions should not automatically be deemed unjustifiable whenever they differ from medical judgment. Rather, we should ask if the proxy's decision is based on factors which the patient would find relevant and important, and if his weighing of risks is one a reasonable person could make.

Thus it is not inappropriate for Mr. Walker to consider his wife's subjective response to hospitalization, since it is a factor which would probably have influenced her decision, even though it is irrelevant to a purely medical judgment. Nor is it inappropriate for Mr. Walker, in weighing the risks, to take into account that his wife's illness was probably viral. The more unlikely that she has bacterial meningitis, the more reasonable his gamble becomes. Additionally, since one reason for recommending hospitalization is to provide careful observation and ready access to treatment, he can consider how closely he will be able to monitor his wife's condition, and how quickly he could get her to a hospital should changes occur.

Mr. Walker, of course, has an obligation to weigh these factors against the risks of taking her home. To do this, he must be accurately apprised of the risks. From the presentation of facts in this case, it is hard to tell exactly how grave Dr. Stanley believed the risks to be. Although the Walkers were told that bacterial meningitis is a life-threatening illness, we do not know whether they were told that it can progress very rapidly to the critical stage, so that a delay in treatment may be fatal or may cause permanent neurological damage. If Mrs. Walker had been told this, it is less likely that she would have been genuinely uncertain as to what to do: there is no indication that her values are so unusual that she would prefer death in a friendly environment to cure in an impersonal one. If Dr. Stanley feels that he inadvertently characterized the risks of going home as less serious than they are, or that Mr. Walker interpreted them wrongly, he should at least try to re-present the facts to both of them before accepting Mr. Walker's decision. And if Mr. Walker remains steadfast, perhaps Dr. Stanley should also try to get Mrs. Walker to take the responsibility herself.

If, however, Dr. Stanley believes that, in his best medical judgment, his characterization of hospitalization as simply "playing it safe" (rather than medically imperative) does not minimize the risks, then he might be constrained to find Mr. Walker's decision, though far from ideal, justifiable. If this is the case (perhaps because Dr. Stanley feels virtually certain that Mrs. Walker's case is viral, or because the couple live very near the hospital), then he should respect Mr. Walker's decision. He should, however, carefully alert both of them to what changes to look for, and impress upon them the importance of an immediate return to the hospital should such changes occur.

Faith Healing for Childhood Leukemia

Within twenty-four hours a ten-month-old boy was transferred from a small local hospital to a university hospital and then to its affiliated cancer center with a presumptive diagnosis of leukemia. Because the diagnosis had not been confirmed by bone marrow examination, information on the type of leukemia—needed for an outline of a specific therapy and a more accurate prognosis—was not available.

When the baby was admitted on a Saturday afternoon, only his mother was present. The child was not acutely ill, and the severe anemia that had concerned the referring physician had been corrected by transfusion before the transfer. The baby seemed much better, according to his mother. However, there were significant signs of tumor. The medical approach currently considered optimal is hydration, medication to counteract excess uric acid, and careful characterization of the leukemia. After that, specific therapy can be offered. The characterization could not begin until after the weekend but some therapy could begin immediately.

This information was explained first to the mother, and a few hours later to the father. After two hours of deliberation, they told the attending physician that they refused therapy. They would, they said, place their faith in God. They had recently seen sight restored to the baby's great-grandmother, when she was taken to a healing service after a debilitating stroke.

They felt that all the cancer center measures would very likely fail and they would then take the child to a faith-healing service. It made more sense to them to refuse the therapy and take the child to the faith-healing service right away. They had prayed for a sign from God to help them make this decision, and took the nurse's failure to start an intravenous infusion on the first attempt as just such a sign.

The physician asked the father why God would allow cancer centers to exist if prayer were a more appropriate mode of exercising parental responsibility. The father replied, "Cancer centers are part of God's plan, so that children of parents who do not believe still have a chance." The parents were then asked whether they could muster a perfect enough faith to mediate the healing. The answer was that such a faith was not necessary—they had a perfect God. The child was discharged without therapy with a return appointment at the center's clinic, but the family did not keep the appointment.

Did the attending physician take the right course of action by acceding to the parents' desires so easily? Should other staff have been requested to negotiate with the family? Should legal remedies have been sought to ensure treatment for the child? What are the limits of religious freedom and parental authority when a child's medical care is at stake?

COMMENTARY

by BARUCH BRODY

I must confess that I have little sympathy for the parents' decision. Coming from a Jewish theological background, I find their position objectionable on theological grounds. The objection was best put by Rabbis Akiva and Ishmael when they said: "Just as if one does not weed, fertilize, and plow, the trees will not produce, and if fruit is produced but is not watered or fertilized it will not live but die, so with regard to the body. Drugs and medicines are the fertilizer and the physician is the tiller of the soil." It is strange to find people actively intervening through natural means to produce desired results in all areas but matters of life and death, and insisting that in those areas alone man should merely pray and leave himself in the hands of God.

My views about the family decision, and the views of the readers of this case study, are not, however, what is immediately crucial here. That issue is a different one, namely who has the right to make the decision for the ten-month-old boy. Only if we decide that we as a society, or some agents of ours (the physician, the hospital, the courts), should be making the decision will it be relevant to ask what *we* think should be done for the child.

One other preliminary point. There are those who believe that adults should not be allowed to refuse medical treatment *even for themselves* in such cases. They believe that society, through its agents, should insist upon making the judgment even for an adult patient. The many people who hold this view will certainly not want to allow the parents the authority to decide to refuse treatment for the child. So this case is a difficult one *only* for those, like myself, who think that adult patients can choose for themselves to rely upon faith healing rather than medical treatment. The question then becomes whether they can also make this decision for their child who is incapable of deciding for himself.

What is the extent of parental authority over the child and to what extent should society intervene to override certain parental decisions? I know of no adequate theoretical answer to this question. We can, however, reject as inadequate two often-held but nevertheless crude models. One maintains that making decisions for the child is a right of the parents, and when society or its agents intervene, they violate these parental rights. The other maintains that making a decision for the child is an obligation placed by society upon the parents, and society may intervene whenever it judges it to be in the best interest of the child.

I would like to advocate a third model for the parental role. In this model, parents do have a right to make decisions for their child. At the same time, the child has a right against the parents that the parents not use their capacity and right to make decisions in ways that are harmful to the child. Society's role here is part of its general role to adjudicate between members with conflicting rights. If we adopt this model, what shall we say about this case? All parties involved believe that the continued life of the child is the value to be promoted; the dispute is about the efficacy of different ways of pursuing this value. (This

differentiates the present case from Jehovah's Witnesses cases.) Therefore, it seems to me perfectly appropriate for society to say (a) if there is ever a case where the child's right to protection takes precedence, it is where the child's life is at stake; (b) in this conflict, where the dispute is about efficacy, and not values, we can easily decide that medical treatment is likely to be the more efficacious; and (c) we therefore expect our agencies (doctors and hospitals acting with the approval of the courts) to protect the child by insisting upon treatment.

But what about the religious freedom of the parents? Surely, if anything is settled in this area, it is that freedom of action (as opposed to belief) where the rights of others are seriously challenged is not justified merely on the grounds that the action is backed by a religious belief.

COMMENTARY

by JAN VAN EYS

Parents' responsibility for the care of infant children is total. Their absolute authority can be overruled, however, if the state decides that parental decisions are not in the best interest of the child. Such state action is a lengthy process, which stirs wide debate unless the action is based on generally unacceptable behavior by the parents, such as overt physical abuse. In the case of life-threatening illness in a child, the choice of medical care by the parents is based on their perception of the illness. It is frequently argued that an inadequate understanding of the disease may prevent parents from making a valid and reasoned decision. Nevertheless, the state does not intervene a priori in making such decisions.

In this case, involving leukemia in an infant, the parents' perception of the probability of poor outcome was not unreasonable. Chemotherapy is never an easy road to follow and is often more difficult in infants. The outcome does vary with the type of leukemia and a prognosis could not be given. But even in the type of leukemia with the most optimistic prognosis, an optimistic outcome would be statistically less certain in an infant than in a four- or five-year-old.

The judgment that a parent is making a decision in the best interest of the child is usually based on the medical personnel's perception of whether parents are seeking a mode of care that has curing as a goal. The harshest judgments are given to those parents who forego the application of proven or near-proven effective therapy. In this case the parents chose to substitute one mode of treatment with curative intent—chemotherapy—for another—faith healing—thereby creating the dilemma.

There is in the United States a strict separation of church and state. In matters spiritual the parents' decision-making power is even more absolute than in matters physical. Not to feed a child would be considered child abuse; not to give a child spiritual instruction is the business of the parents and not of the state. In addition, although the state makes judgments about what constitutes adequate nutrition, there are very few state judgments about what constitutes adequate spiritual sustenance.

Does separation of church and state imply a separation of church and medicine? Is medicine in fact allied with the state or with the spiritual realm? There is no doubt that the treatment offered the child was wholly biological. However, this does not mean that medical therapy lacks a strong component of faith, even at its most overtly physical, such as in cases of surgery. Clearly medical and spiritual matters are not nearly as separate in the eyes of patients as they are in the eyes of many physicians.

The juxtaposition of faith healing and medicine puts the burden of response squarely on the physician. Does the physician accept the proposition that these are comparable alternatives? As an analogy, Laetrile and classical chemotherapy for cancer are comparable alternatives in the sense that both are attempts to cure the disease. Given such a choice, the decision can be based on recorded past experience. Presumably, an objective decision can then be made about the preferability of conventional chemotherapy over Laetrile.

Obviously the juxtaposition of faith healing and classical medicine does not readily allow an objective evaluation. On the other hand, to reject faith healing a priori as an element of care by the parents would force the physician to confront his or her own belief system. To reject faith healing as an alternative that is outside the system of organized medicine, and thereby to argue that faith healing is not a selection of care but a rejection of medicine, demands an a priori rejection of the concept of faith.

Usually parents use faith healing as a form of support, a "hedging of one's bets." As such it can be ignored, endorsed, or condoned by physicians. In this case the confrontation was stripped of any smokescreen, and the question was presented in its barest form. The parents rejected the concept of classical medicine and faith healing as complementary modes of care: classical medicine, they said, is God's plan for those of little faith.

The fact that an infant is involved in this argument is not as important as the argument itself. Its application to infants recalls the long-standing theological debate over infant baptism. There are arguments that a child should not be baptized until he or she can purposefully make that choice. However, if there is no time to let the child select the alternatives, such debates become irrelevant. The implications inherent in faith healing are clear: the parents feel a responsibility to ensure that their child follow their convictions. No doubt different physicians would have reacted and responded to this challenge differently. The response is clearly dependent on the physician's own deep-seated spiritual beliefs. Any absolute solution would reflect the attitude of the person who proclaims such wisdom, not a fundamental truth about human existence and parental responsibility.

3

Mental Health and Medical Interventions

Fear of Flying: The Psychiatrist's Role in War

The following report is reprinted from the Air Force's PACAF Surgeon's Newsletter, **December 1966, p. 5.**

Fear of Flying: A twenty-six-year-old staff sergeant AC-47 gunner with seven months' active duty in Vietnam, presented with frank admission of fear of flying. He had flown over one hundred missions, and loss of several crews who were well known to the patient, precipitated his visit. He stated he would give up flight pay, promotion, medals, etc., just to stop flying. Psychiatric consultation to USAF Hospital, Cam Ranh Bay, resulted in thirty-six days' hospitalization with use of psychotherapy and tranquilizers. Diagnosis was Gross Stress Reaction, manifested by anxiety, tenseness, a fear of death expressed in the form of rationalizations, and inability to function. His problem was "worked through" and insight to his problem was gained to the extent that he was returned to full flying duty in less than six weeks. This is a fine tribute to the psychiatrists at Cam Ranh Bay. (633 Combat Spt Gp Dispensary, Pleiku AB.)

COMMENTARY

by PERRY LONDON

As the *Newsletter* says, success in returning the gunner back to duty is a fine tribute, indeed, to psychiatrists' efficiency as technicians. The question is: does it also testify to their deficiency as moralists? Proper morality, in some views, would have made them work against the official position of the government and the military in the Vietnam war; and holders of such views are outraged that physicians would sell their services in such an unjust cause. Since we lost the war only recently, and therefore still blanch doubly at having fought it altogether, it is easy to be seduced into moralistic "right-think." Losing a war is forgivable, and time dulls the bitterness of unjust victories; in those cases the moral imperatives are not so clear and obvious. Israeli doctors who returned gunners to their tanks and planes in 1973 or their counterparts in the Mexican-American War in 1845 are not subjected to the same scrupulosity. And perhaps a century from now, Wehrmacht doctors will be seen as no more evil than they must have felt in 1941. Even the Nuremberg trials may seem, like Magna Carta —a celebration of the victors' power. Might may not *make* right, but it certainly influences comment on it.

Outrage at the Air Force doctors reflects what I call the "new

conventional morality." The old conventional morality said, simplistically, that a soldier's duty was to uniform, mission, or country *via* chain of authorized command; the new morality implies that soldier-doctors should themselves define where their duty truly lies. "Right-think" adherents assume the psychiatrists would have decided to subvert the government by preventing the gunner's recovery, or by treating him and at the same time trying to persuade him to alter his public position from one which would produce an "unfitness" or "disability" discharge (with full veteran's benefits) to one which would subject him to general court-martial (with full prison sentence). If the psychiatrists were themselves to define their moral duty, and then do exactly what they did because they supported the Vietnam war, the new morality would be hoist on its own petard. But moral outrage may blind us to this fact, as it blinds us to the fact that there are people who actually believe in Nazism, racism, and paganism as moral imperatives. So much for logic. Even more to the point is the psychologic fact that psychiatrists, like most of us, are not much cut out for the practical heroics of subversion or rebellion, or even for pondering too much about them. To argue that most people can, or should be, routine arbiters of their own morality, I believe, slaps harshly in the face of reality.

Individual morality is built on the bedrock of social norms, and is sustained by reinforcements in social custom. It perishes slowly but surely when social norms change and the rewards and penalties for erstwhile good and bad behavior are changed to meet new rules. Most Nazis, I fancy, abhorred cruelty to dumb animals (not the same as Jews); most Arab terrorists love their children (not my children); most air force gunners don't like to kill people (and still less to get killed). Most psychiatrists try to do the jobs expected of them—on the couches of Fifth Avenue, in the Cuckoo's Nest, and at Cam Ranh Bay. Some people in all these groups change their minds and try to leave the field, generally quietly, keeping a low profile to ward off retaliation; but sometimes noisily, almost begging for martyrdom. Yet most of humankind, most of the time, are too busy trying to manage the routines of daily living to spend much energy on moral calculations. Most morals get borrowed from the neighbors, the organization, or the big shots of our other-directed society. Just as politics is the exercise of leadership, and most of us are rather passive followers, morality is the exercise of normative behavior, and most of us are rather passive actors in the creation of our norms. The Children of Israel liked Egypt and did not mind slavery in principle; it was the beatings, the strawless bricks, and the baby snatchers that did them in. So it is with most of us, most of the time.

I do not mean to argue that people should never be held individually accountable for their acts, or that the Vietnam war was a just one. I do mean to say that a decent society makes the individual the last arbiter of morality, not the first one. In 1966 (when the *Newsletter* was published), I thought, like many others, that we were on the right side of the Vietnam war. By 1969, like many others, I had changed my mind. In 1975, it is unseemly, if not immoral, to retrospectively condemn the doctors of last decade's war for doing what then looked like their duty in a cause which they probably supported. Physicians are no more ignorant, or ill-intentioned, or immoral, than the rest of us. The case is a study in tragedy, not morality.

COMMENTARY

by H. TRISTRAM ENGELHARDT, JR.

In reading this case, one might be tempted to consider it simply an example of the misuse of medicine in the service of a political goal. That would be an oversimplification because the individuals concerned, the psychiatrist, the persons who asked for their consultation, and in the end perhaps the patient, probably saw themselves as acting in accord with reality. The case illustrates the role that value judgments play in the concept of disease. The judgment that someone has a disease presupposes, among other things, (1) that the person afflicted is the subject of phenomena that are abnormal and (2) that those phenomena are explainable in terms of the laws of pathophysiology and psychology. That is, the statement that some condition is a pathological state presupposes more than a mere description. The condition must be held in some sense to be a state of suffering and to be abnormal, where "abnormal" means other than "unusual." Even if most persons had some cardiovascular disease at age seventy, one could still term the condition a disease condition. It would be "abnormal" where "normal" expresses an ideal of function. Thus one will term diabetes, menopause, alcoholism, etc., diseases depending on what one judges proper to the human condition. Similarly, one will term angina a disease state because it is a painful and incapacitating condition, while one will not term teething a disease, because the latter is held to be a normal and proper state of pain, since it is closely bound to achieving a normal human goal—having teeth. Similarly, polydactylism and vitiligo will be held to be deformities or diseases on the basis of a judgment about what human form should be like. In contrast, an in-

telligent or very beautiful person will be held to be above normal, because of a set of human judgments about what humans should be. Finally, as Talcott Parsons has indicated, calling people sick assigns to them a social role which excuses them from blame for their condition. One may blame a cigarette smoker for becoming ill with bronchogenic carcinoma of the lung, but not for being ill. Consider in this regard the disease of alcoholism or drug addiction; consider as well the history of diseases which we now in retrospect can see to have reflected particular cultural judgments: the disease of masturbation and draepetomania (the pre-Civil War disease of slaves running away).

In "Fear of Flying," the flier was appreciated as being ill in that he was in distress (that is, suffering—afraid that he would be shot down in combat) and was unable to function normally. Normal function was here defined as the ability to engage in combat. Moreover, the failure to function was held to be caused rather than to be a chosen pattern of conduct. To consider a state of affairs a disease is to hold that it is caused by pathological processes, not freely willed action. Diagnosing the flier as ill with a "Gross Stress Reaction" thus authorized (1) the use of medicine to restore health and the ability to function normally, and (2) excused the individual from responsibility for not having functioned.

One should notice that once one chooses to consider the condition a disease condition, the description of the "facts" of the matter changes. The facts become embedded in a theory which then infects them with a special valence. The individual who is the focus of concern becomes a "patient," his judgment concerning the risks associated with flying become "rationalizations," his refusal to fly becomes an "inability to function." It is not clear from the material available whether the individuals seeking treatment for the gunner actually thought he was ill, or whether someone used the disease model in order to avoid court-martial for the flyer. In either event, this case illustrates the social role of "disease" concepts and the ways in which they presuppose value judgments about norms for humans and the human condition. This is inescapable. The best we can do is to amend those concepts of disease which conflict with our more general human values concerning freedom and individual responsibility.

One should recognize this case as a flamboyant example of the generally value-laden character of talk about disease and health. It is not as if one could simply isolate those diseases which are objectively disease categories and those that are not. Rather, some disease concepts fail (and should fail) because they conflict with general human values.

COMMENTARY

by ROBERT G. NEWMAN

This case illustrates the inherent dangers of psychiatrists' equating deviance with psychopathology and proceeding unquestioningly from the premise that "curing" such deviance is a universally valid goal. In fact, the clinicians in this instance display precisely the type of symptomatology they ostensibly seek to treat: an inability to recognize and respond appropriately to reality, sublimation, and escapism.

1. The reality which confronted the patient in this case made "fear of flying" a reasonable, appropriate, and psychologically healthy response. The corollary is also true: the use of psychiatric intervention in overcoming the fear elicited by such a situation leads to a condition which might best be termed iatrogenic psychosis.

2. Instead of recognizing the extraordinary dangers which the patient somehow managed to survive during seven months of combat, and accepting his right to refuse to participate further, the Cam Ranh Bay psychiatrists determined that the cause and the cure of the "problem" lay in the head of their patient.

3. In "blaming the victim," the medical officers avoided the conflict which would have been created had they refused to accept the patient as a psychiatric referral.

In retrospect, this case history generally elicits incredulity and laughter. The great threat to civil liberties is easily overlooked. The awesome power vested in psychiatrists, despite recent court challenges, is frightening. It is virtually impossible to refute a psychiatric diagnosis, and the harder one tries, the more the attempt is viewed as additional confirmation of the severity of the "mental illness." Involuntary "treatment" can follow, in which case the individual must either adopt conformity or suffer the consequences. One can only speculate on the consequences for the unfortunate sergeant had he not been able to "work through" what was termed *his* problem and conquer his fears.

It must be conceded that the article does not unequivocally indicate whether the sergeant was referred to the psychiatrists voluntarily or not. It would certainly appear, however, that he presented his superiors with a statement of fact, with a rational decision that the enormous risks inherent in continued air combat outweighed the material benefits of increased pay, the added privileges of higher rank, or the pride which might be derived from commendations. What appears to be inappropriate under these circumstances might indeed have been laudatory if he had expressed a wish to *continue* flying instead of announcing a decision to stop.

An analogous area in which the conflict between practitioner and patient is most prevalent today is the field of drug abuse. Drug users are increasingly being forced into treatment programs under the threat of prosecution, and as a condition for release from prison after sen-

tencing. This approach, which has been heralded as a humane alternative to applying criminal sanctions for the violation of laws, is in fact a perversion of the physician-patient relationship. As with the Air Force sergeant, the illness and the criteria for successful treatment are determined unilaterally by the psychiatrist, frequently in direct opposition to the expressed views of the patients. Addict-clients are considered to be successfully rehabilitated when they accept whatever grim reality others have determined to be their lot, just as the sergeant was hailed as a therapeutic triumph when, after being subjected to "psychotherapy and tranquilizers," he resumed as gunner in an AC-47.

When the patient does not have the unequivocal option to refuse treatment, one must proceed from the assumption that voluntarism is lacking. Under these circumstances the concept of success and failure loses all meaning. Whether the "problem" is fear of flying, drug abuse, homosexuality, masturbation, or any other behavior, it must be left to the individual to decide if it is acceptable or not, and whether change is a desired goal. The attitudes of the psychiatrist regarding the behavior, and the value which the psychiatrist may personally place on modifying that behavior, are irrelevant. The circuitous logic evidenced in this case history, which cites as proof of success the fact that the patient ultimately came to share the psychiatrists' views, must be rejected. Nor does the self-righteous assertion that the psychiatrists' motivation is benevolent mitigate the invidiousness of involuntary treatment. As Thomas Szasz has pointed out in *Law, Liberty and Psychiatry:* "Treating patients against their wishes, even though the treatment may be medically correct, should be considered an offense punishable by law. . . . Let us not forget that every form of social oppression has, at some time during its history, been justified on the ground of helpfulness toward the oppressed."

'Ain't Nobody Gonna Cut on My Head!'

A 56-year-old farmer, accompanied by his wife, consulted the Neurology Service of Veterans' Hospital because of memory difficulty. For two years the patient had been having increasing trouble with technical aspects of farming. More recently he had been talking about his brother George as if he were alive although he had died two years earlier. He gave his own age as 48, and the year as "1960, pause . . . er, no, 1970." Examination revealed that the patient walked with a wide-based gait (a standard sign of brain pathology) and decreased cerebral function but was otherwise normal. The patient had no difficulty with simple coin problems and could repeat six digits.

Pleading pressing business, the patient declined hospitalization to determine the cause of his decreasing cerebral function. His wife tried to persuade him to enter the hospital, but when the resident suggested that she might assume guardianship for her husband through court action she declined.

Six months later the patient's condition had worsened. Through the urging of the county agent the patient had leased most of his farmland to his neighbors and now did no work. His gait had become so wide-based that acquaintances mistakenly thought him inebriated. He urinated in his pants about once a week, and recently seemed not to care. He sat watching television all day, but never paid any attention to the program content.

Examination at this time showed an apparently alert man without speech difficulty but with considerable mental deterioration. The patient gave his age as 38, the year as 1949, the president as Eisenhower, and the location as a drug store in his home town. He failed to recognize the name Lyndon Johnson, but upon hearing the name John F. Kennedy he spontaneously volunteered knowledge of his assassination. The patient could not subtract 20 cents from a dollar but could name the number of nickels in a quarter. He could recite the months of the year and could upon request from his wife give fairly long quotations from the Bible.

The resident and the attending physician urged hospitalization. They told the patient they would evaluate him for treatable causes of mental deterioration and memory deficit. In view of his wide-based gait and urinary incontinence in association with dementia, it was likely he had occult hydrocephalus. It was explained that this disorder caused decreased mental abilities by interference with absorption of cerebrospinal fluid. The mental deterioration in these patients is partially (as in his case now) or completely (as in his case six months ago when first seen) reversible. The treatment is to place a plastic tube through the skull to drain the cerebrospinal fluid from the brain to the vascular system; this was explained to the patient with diagrams. The patient immediately rejected the surgery, summarizing his thoughts with these exact words: "Ain't nobody gonna cut on my head." The patient's wife again attempted to persuade the patient to accept hospitalization and, if tests confirmed the clinical impression, surgery. The attending physician argued to the wife that the patient did not have the mental competence to decide his own fate and the wife should become the patient's legal guardian through court action and force hospitalization. The wife politely but vigorously rejected this course of action, pointing out that in her family the husband made all important decisions.

The resident and the attending physician differed in opinions at this point. The resident thought the patient should be followed in the out-patient clinic until he perhaps changed his mind. The resident pointed out that though the patient had decreased mental abilities he still retained enough intelligence to decide his own fate. The attending physician wished for court action to make the patient the ward of one of his relatives or, if necessary, the temporary ward of the hospital, and to force hospitalization and therapy.

COMMENTARY

by JAMES M. GUSTAFSON

THE PRINCIPAL substantive moral issue in this case is the status of the right of the patient to determine his own bodily destiny. He refuses to consent to a procedure which is likely to relieve his disability, though apparently he understands in lay terms what is involved in the surgery. At his level of competence he is "informed," but he refuses to give "consent."

The principle of informed consent is based upon one moral assumption and upon one philosophical judgment. The moral assumption is that individuals have a right to refuse treatment even when in the judgment of others that treatment is in the patient's own best interests. A person has a right to determine his or her own destiny. The ground of this assumption is historically located in the libertarian tradition of Western culture; it stems from the same tradition that values civil liberties, that believes that the state exists properly only on the basis of the consent of the governed, and so forth. The philosophical justification for the individual's right to self-determination has been made in various ways: the right is "natural"; capacity for self-determination is what makes humans distinctive as a species and from this is derived both its value

and the right; individual rights are conferred by God; excessive incursion on self-determination leads to repression and in turn to social unrest, and for this reason the right is to be protected.

The serious philosophical judgment on which the principle of informed consent is based is that persons actually have a capacity to determine their own destinies. Every case of this sort opens the historic debate about "free will' if the case is carried beyond the immediate clinical circumstances.

This case can be analyzed on the basis of two questions which follow from the two previous paragraphs. 1) Are there *moral* grounds for exerting persuasive, or legal and coercive, measures to override this man's presumed right of self-determination? Do his obligations to his family and to the community (or, to make the point in a weaker way, do the interests of his family and the community) provide a sufficient basis for intervention without his consent? How one would answer this question would depend upon the status of the right of self-determination in relation to the claims of communities (his family, the neighbors, etc.) to limit and even override that right. 2) Are this man's capacities to judge rationally and to act in accordance with a rational judgment impaired by his illness to the extent that he cannot properly exercise his moral right to self-determination? Is he, to use the common term, really "competent?" Does his impairment provide "excusing conditions" so that just as he is not held accountable for his wide gait, so he is not accountable for his rejection of the proposed therapy? Given the assumption of "free will" in the consent procedure, can his will be judged to be "less free" than is necessary and sufficient to make a sound judgment? The attending physician could justify his "wish" for court action on the basis of either or both of the matters raised by these questions.

In this case I would argue in favor of the attending physician's "wish." My principal argument would be on the basis of the patient's limited capacities to exercise his right of self-determination. Note that an empirical judgment about those limits is involved. A hypothesis (and that is all it is) would be required to support the argument, namely, if this man's capacities were not so impaired he would consent to the surgery. Procedurally, I would support the steps taken in the report of the case; that is, first seeking voluntary consent of the patient, then of his family, and only as a last resort seeking a court order. I am prepared also, however, to argue that this man has obligations to his family and to the community that he ought to take into account in making his own judgment. His failure to consent is, it appears, costly to others; others are dependent upon him and thus also have a claim on him to consent to a procedure that would permit him to fulfill his duties to them. Procedurally, if such a line of argument failed to persuade him, and then his family, there would be a moral justification for court action. At the base of my conviction here is a significant qualification of the individual libertarian tradition in the direction of a more "social" view of persons and of duties and obligations of persons to other individuals and to communities.

COMMENTARY

by FRANCIS C. PIZZULLI

AT FIRST BLUSH, the attending physician presents a fairly convincing case for initiating state intrusion into the patient's brain. As the title of the case implies, the proffered therapy is fairly characterized as "brain surgery" and thus avoids categorization as "psychosurgery," replete with its politically value-laden premise of experimental treatment for the purpose of controlling socially deviant behavior. If indeed, the preliminary diagnosis of occult hydrocephalus is sound, the operation would be tailored to rectify an accepted organic brain pathology. Though this entails the concomitant effect of controlling aberrant behavior (e.g., urinary maintenance and dementia), the presence of excess cerebrospinal fluid calls into play a well-defined medical/disease model which makes less persuasive the need to inquire into the motives of the physician as a check against the potential transmogrification of psychiatrists into thought-controllers.

If one were to accept the physician's evaluation of the mental incompetency of the patient, coerced institutionalization and treatment could be defended on a number of grounds. The procedure is relatively non-intrusive; to wit, it is a safe, non-experimental operation which involves no destruction of brain tissue and is intended to control behavior that ranks rather low on the continuum of volitional and autonomous functions. Not only is this intrusion minimal, but an array of humanitarian and utilitarian impulses militate for intervention. Does not the state have a moral obligation to the patient's former self to restore it? Or an obligation to construct a new self for the person, at which point he would be released to exercise his autonomy to its fullest potential? And would not this restoration to optimal functionality redound to the benefit of his family and community?

Even if we were to assume the patient's competency, the cost of overriding his competent judgment would be measured in terms of a single interference with personal autonomy at a particular time, presumably to be outweighed by the personal and social interest in a long-term increase in autonomy achieved by effective treatment.

Is there a decisive rebuttal to the physician's benevolent despotism? From a traditional legal perspective the case for involuntary commitment (i.e., enforced hospitalization) in this instance is rather weak. There is no mention of anti-social activities by the patient, which would warrant a finding of "dangerousness to others." To say that occasional urinary incontinence and mindless fixation upon the boob tube—behavioral traits found in many "normal" persons—constitute dangerousness to oneself reflects a most extreme paternalistic bias.

Even if the criteria for involuntary

commitment are met, the case against intervention by no means falls. We cannot conclude that because an individual may no longer be competent to care for himself generally (e.g., due to memory deterioration), he is thereby incompetent to pass informed judgment upon such an intrusion as the proposed organic therapy. The notion of limited competency, besides having legal recognition, is rooted in the empirical observation that certain mental illnesses do not completely obliterate a person's ability to make decisions. While the patient may no longer recall dates and ages, it is hard to envision how memory deficit can totally discredit the capacity to understand the consequences of an operation, and to immediately summarize the resident's explanation and conclude with a refusal, as the patient has done. Even if we were to adopt the simplistic view that there is no competency where the refusal only occurred because of the mental deterioration, there is no evidence to indicate that the patient is other than strongly individualistic, and would not have decided likewise prior to the onset of deterioration. Moreover, the competent spouse's concurrence in his decision might be construed as evidence of agreement with his lifelong views on brain surgery.

To respond to the invocation of a classic Benthamite calculus that would override limited, albeit informed, judgment to refuse therapy, we might profitably view the case from a rule-utilitarian perspective. While it may be true in this particular case that only a minimally intrusive operation is needed to arrest mental deterioration and partially restore memory function, we should ask what the consequences would be of a practice of substituting the state's judgment for individual informed consent in order to achieve the incremental gain in utility involved in curing those who suffer from marginal mental impairment. Is it too far-fetched to conclude that the result would be a society in which democratic values of personal autonomy, freedom, and privacy would be subjugated to the ideal of state control over various kinds of behavior?

There is one final barrier to coerced surgery, assuming for the sake of argument that there are grounds for civil commitment and that the patient does not have the limited competency to give informed refusal to treatment. Shall the next-of-kin be designated as the proxy, with the power to give or withhold consent? To argue in the negative, because it is suspected the spouse will only rubber-stamp the incompetent's decision, conflicts with the legal presumption of identity of interests among kin. Likewise, to propose a third-party guardian who will rubber-stamp the physician's decision, on the ground that it will enhance the well-being of the patient and his family, arrogates to the physician the right to define that well-being, instead of allowing it to be defined within the privacy of the family.

In sum, only a highly paternalistic society could tolerate the intrusions upon autonomy and privacy that would flow from a practice of coercion in cases such as that at hand.

Can Convicts Consent to Castration?

In 1973, two forty-five-year-old men—Joseph A. Kenner and Paul R. de la Haye—both pleaded guilty to sex offenses involving minors. Having had prior histories of such behavior, both were committed to California's Atascadero State Mental Hospital. After two years of treatment, however, hospital officials reported that the two convicted child molesters had failed to respond to psychotherapy, and had remained "dangerous to society" with little or no prospect of improvement. The men were released and returned to county jail to await sentencing.

On grounds of the hospital's negative prognosis, the judge indicated in court that he would sentence the men to indeterminate terms, with a good likelihood that they would pass the remainder of their days within the confines of the prison walls. Given so bleak a life prospect, the two men signed requests for castration along with waivers releasing their lawyers, the court-approved surgeon, and the judge from any liability. The surgery, known as a bilateral orchidectomy, was to constitute part of a rehabilitation program which might contribute to a possible grant of probation.

The judge delayed the sentencing pending further review. Such operations, formerly common practice under judicial orders in California, had generally been opposed by the courts since the American Civil Liberties Union brought suit five years previously against a San Diego judge and a surgeon involved in a similar "free will" operation.

The difficulties were compounded when Dr. Alan H. Walther, who had originally consented to perform the operation, withdrew his agreement after consultation with his medical colleagues, members of the San Diego County Urological Society, and the Malpractice and Ethics Committee of the San Diego Medical Society. Perhaps the most persuasive argument was offered by the medical society officials who informed him that although the Society's group insurance covered him against any malpractice claims, he might still be liable—without insurance protection—to a lawsuit for mayhem or assault and battery, regardless of the waivers.

COMMENTARY

by GERALD KLERMAN

The use of castration for "treatment" of convicted child-molesters is a controversial issue, one which "cuts" to the core of our values of autonomy and freedom. However, before the ultimate issue can be resolved—namely, whether or not any individual can ever consent truly autonomously to castration as part of a program of behavior control—it is necessary to disentangle a number of associated issues which, unfortunately, are so confounded in Case 536 as to render clear analysis difficult. For the purposes of this discussion, at least three questions must be separated:

What is the evidence on the efficacy of surgical castration for modifying compulsive sexual behavior? Were the two prisoners truly capable of giving free and informed consent for bilateral orchidectomy while still confined and without other prospect for release? Did the medical societies act appropriately in the decision of the surgeon, Dr. Walther?

Let us take up each of these issues in turn.

The issue of efficacy. A major scientific issue has to do with the evidence for the efficacy of the procedure. How does it compare to various psychotherapy or rehabilitation methods, or to the effect of incarceration *per se*? Let us assume for the purposes of argument that the evidence (mainly from Scandinavian studies) is that incarceration alone, and standard psychotherapeutic and rehabilitative methods such as those offered in optimal mental hospitals and correctional institutions, are relatively ineffective, while bilateral surgical orchidectomy is effective in reducing the likelihood of future sex offenses. Then, in my opinion, Kenner and de la Haye have the right to review this evidence and to make a judgment about their own personal destiny.

The autonomy and free will of the prisoners. A more serious biomedical ethical issue is the one raised by the American Civil Liberties Union in their suit claiming that prisoners in California institutions are not capable of giving truly free consent. On one hand, it is true that prisoners sentenced for indeterminate terms are not capable of completely free choice, since their range of options is severely restricted by the indeterminate sentences. On the other hand, there is no evidence that the two convicts were unable to appreciate the nature of their offense, or the consequences of the various alternatives. This is partially a matter of psychiatric judgment as to their intelligence, comprehension, and ability to anticipate the consequences of behaviors. Furthermore, the question arises whether any coercive efforts had been applied. Ultimately, a societal judgment will have to be made as to whether incarceration under indeterminate sentence is in itself coercion, and even a violation of the Eighth Amendment.

It is my view that prisoners have the right and ability to make choices, even while incarcerated.

The role of professional societies. In my opinion, the two medical societies acted inappropriately in restricting the autonomy of Dr.

Walther. In addition, their advice obscured the ethical issues with regard to surgical castration for sex offenders. I suspect, but cannot prove, that the timing of this case in early 1975 coincided with the California medical profession's reaction against the increasing number of malpractice suits, and that their decision in this case was strongly influenced by their concerns about malpractice insurance.

The concerns raised by the two medical societies—the adequacy of liability insurance and possible lawsuit for mayhem and/or assault and battery—are relatively easily disposed of by appropriate legislation or court decisions authorizing the conditions under which physicians may participate in such procedures without being so liable.

Taking these factors into consideration, and assuming (1) that the available evidence indicates that the surgical procedure is more efficacious than the other alternatives; (2) that Kenner and de la Haye were not subject to coercion other than being under indeterminate sentences; (3) that they were fully in possession of their mental faculties; and (4) that they had attorneys available, my conclusion is that they have the right to make this choice, and that Dr. Walther has the right freely to consent to perform the operation without the influence of liability constraints or pressure from his colleagues in the professional societies.

But let us consider other possible situations that focus the issue still more sharply, for they involve requests for biological intervention on the part of free citizens, not in custody and under no legal coercions. Imagine individuals similar to Kenner and de la Haye, who are intensely troubled by their sexual impulses and have in fact committed sex offenses but have not been apprehended. Anxious to escape their terrible conflict and fear of discovery, learning that surgical castration or new anti-testosterone drugs might relieve their uncontrollable drives, such persons might voluntarily apply to a medical center for one or the other procedure. Would—and should—they be refused?

In fact, many physicians have hesitated over this issue. Yet if responsible scientific judgment finds the therapies to be effective and psychologically appropriate, and if they are to be accompanied by conscientious support, it seems to me there should be no constraints upon such individuals having access to the therapies they seek.

However, there is a powerful source of constraint on the part of many psychiatrists, psychologists, lawyers, and ethicists, who feel doubt and anguish at such a prospect. What is the source of this psychological constraint? I propose that it arises out of some concept we have of the essence of personality, or "soul." While this essence is considered in some way to be independent of its biological nature, we recognize that it partly depends on physiology — on adequate brain function but also upon the integrity of certain aspects of anatomy, closely bound to our sense of autonomy and identity, such as the face, limbs and sex organs. We romantically believe that incarceration, even with its humiliations and restrictions, is less likely to impair our inner essence than psychoactive drugs or than procedures altering certain parts of the body. I believe it is time to review whether or not this assumption is true—that the incarcerated individual is still capable of retaining his autonomy. I suspect that we have been overly influenced by accounts of rare individuals who have maintained their sense of autonomy while incarcerated, and tend to ignore the many thousands whose capacity for autonomy and freedom has been overwhelmed by the indignity of prolonged incarceration. If this is true then I, for one, would opt to allow the prisoners the right to choose either surgical castration or pharmacological treatment over lifelong confinement.

COMMENTARY

by GERALD DWORKIN

Let me begin by noting that there are both empirical and legal questions which may render this case moot. The faith placed by the court, the doctor, and the offenders in the efficacy of orchidectomy in eliminating or greatly reducing the danger of recidivism is misplaced. The empirical evidence about the effects of such an operation on libido and potency is scanty, mixed, and inconclusive. Generalizations from this weak data base as to the effect of the operation on child molestation (an act whose psychological motivations are unclear and complex) are even more dubious. Courts ought at least to get their facts straight before creating legal and moral problems.

There are also serious constitutional questions which I shall set aside. It can reasonably be argued that the holding of the Supreme Court in the abortion cases (physician-patient decisions concerning abortion are constitutionally protected against state interference) can be extended on similar rights-to-privacy grounds to operations such as the one in question. Whatever the moral qualms, there may be compelling constitutional grounds for not infringing on the autonomy of patient or physician in the area of voluntary surgical procedures.

Morally speaking, this case raises at least three quite distinct issues—consent, paternalism, and human dignity. Although conceptually distinct they intertwine in thinking about the practical question—what is to be done?

Doubts about the adequacy of the voluntary nature of the consent reflect three separate considerations. Can there ever be meaningful consent in a total institution such as a prison? Are the stakes (long-term confinement versus the possibility of early release) so weighted that coercion nullifies free consent? Are the nature of the operation, and the psychodynamics which motivate it,

such that we must scrutinize this choice more carefully than others?

Although the court in the Kaimowitz psychosurgery case seems on one possible reading to have held that free consent is unobtainable in total institutions, this seems to me far too strong as a quasi-factual statement, and one that unnecessarily restricts the rights of inmates in such institutions. Nevertheless, in this particular case, one would like to know a good deal more about the psychodynamics of both the offenders and the authorities. Is the operation viewed by the prisoners as a form of self-aggression? Are the authorities perhaps unconsciously seeking the retributively appropriate form of punishment? At the institutional level this procedure provides the ultimate excuse against charges of leniency if the men are released and repeat their offenses.

Again, not every choice between alternatives as unpleasant as these is unfree choice. The law already allows certain choices made under the pressure of avoiding or reducing incarceration—plea bargaining is one example. So if everything were just right it seems possible to characterize the consent as voluntary. The question that ought to be addressed is not whether consent is possible, but whether it is desirable. One objection to allowing such choices is paternalistic. We ought to protect an individual's best interests against his own attacks. Such arguments are strongest when there are reasonable grounds for supposing the individual is misinformed as to the nature and consequences of his actions. We act in behalf of values which the individual accepts and gamble that he will come to see we have acted in his best interests. But in this case it appears to be a rational decision even when measured in terms of the values of sexuality. The sexual options open to people incarcerated for long periods are neither many nor pleasant. When the additional burdens of life in prison are thrown into the calculation, it can seem irrational to make any other choice.

Still this does not settle the matter. For even if the choice is made freely, and it is a reasonable choice for the individuals concerned, there are consequences for the rest of us. I am not thinking merely of the various "slippery slope" arguments. If we allow this operation to be performed, will not the pressure increase to perform it on unwilling persons? I am thinking, also, of what it says about our legal institutions, about us, if we allow individuals to buy their freedom by cutting out a part of themselves which is connected so intimately with their (and our) conceptions of who and what they are. I am not denying that for some individuals sexual renunciation may be rational, and indeed because of its importance gain a symbolic significance not otherwise possible. For non-prisoners who are so appalled by the force of their own sexual desires, or frightened by them, autonomy may be increased by renouncing their sexuality. But on the assumption that these two individuals are simply buying freedom, then by allowing such exchanges we also pay a price—treating people as less than human. Given the existence of alternatives (aversive behavior modification, the administration of cyproterone—a temporary testosterone antagonist), the questions about the efficacy of the operation, and the qualms about consent, there is, as yet, no reason to pay such a price.

Is a Crisis of Conscience a Medical Problem?

Kalle Karlsson was one of a dozen children born to a very poor Swedish family. He left school early in life to help support his family. Politics seemed the most promising exit from his poverty, and like many others in the economically backward northern region where he lived, he joined the Communist party.

Karlsson devoted his adult life to hard work and the labor movement. A bright and industrious man, he soon became a building contractor, then director of his own company; he reached high positions in both the trade union and the Communist party. Karlsson grew accustomed to his prosperity. He was married and the father of two children; he owned a villa, maintained a savings account, and after his children left home, he most enjoyed sitting before an open fire with a glass of punch and a good cigar, while his wife knitted for their grandchildren.

Gradually Karlsson found his Communist party activities less satisfying and the thought of going to meetings depressed him. Because his work in the party and labor movement had given him his chance for success, he regarded himself as a defector and traitor. He thought about completing his treason by quitting the party and joining the conservatives, whom he now regarded as his rightful economic allies.

As a result of this conflict, Karlsson developed a deep depression and was admitted to a psychiatric clinic. The standard treatment at that time for his condition—electroshock therapy—was successful. But he still had not resolved his qualms of conscience and he wished to discuss them. He was placed under the care of a young intern whose political beliefs differed radically from his own. A staunch conservative, the physician was not at all sympathetic to the Communists. He believed it was in his own interest, and in the social interest, to decrease the numbers of Communists and Socialists and increase the ranks of the bourgeoisie. In Karlsson, a middle-aged man tormented by guilt and inner conflict, he perceived a potential convert. But this very fact made him acutely aware of the danger of abusing his psychiatric powers.

COMMENTARY

by CLARENCE BLOMQUIST

Twenty years ago when Kalle Karlsson became my patient, there appeared to be several courses of action open to me. I was perplexed about which goal I should pursue:

1. To make him a well-adjusted and politically active Communist.
2. To make him a well-adjusted but politically passive Communist. (This was his wish.)
3. To make him a well-adjusted apolitical middle-class person.
4. To make him a well-adjusted middle-class person whose political loyalty was transferred to one of the bourgeois parties where most people of his current social class belonged. (My wish, at that time.)
5. To keep him unhappy, thus forcing him to decide where he stood.
6. To help him redefine his own lifestyle.

I was young and knew little of human nature or psychological phenomena like transference and countertransference. Nor was I sophisticated about medical ethics, which in any case were not discussed as they are today. Like most Western physicians I was educated in the Hippocratic tradition and believed that I should act in the patient's best interest without regard to political or economic consideration. I feared the consequences of allowing my personal preferences to affect my treatment. All these influences led me to choose the second alternative. It appeared to be in Karlsson's interest; and, since this was Karlsson's own desire, it was not the expression of my preference. I did not urge him to confront and possibly resolve—with whatever outcome for his politics—the underlying conflicts in his life. I advised him that he had done his job and was now entitled to sit at home smoking cigars while the younger generation carried on the battle.

In retrospect, my estimate of my own powers and my fear of using them seemed exaggerated. I now think that I should have formulated a more general goal for him, assisting him to redefine his lifestyle and leaving to fate the possibility that he might have come to share my own political attitudes. Instead, my fear of coercing him may have prevented me from truly helping him to come to terms with himself.

The questions I now see as important in cases like this are: do qualms of conscience—let us call them ethical problems—belong to the realm of medicine? Has the psychiatrist any expertise in dealing with them? Given the risk of coercion, how circumspect should the psychiatrist be, how willing to be guided by the patient's own desires?

Karlsson surely had a disease—severe depression—but the causes were just as surely not medical. Had he not been able to find a satisfactory way of dealing with his problems, he would have probably succumbed to the disease (depression) again. Should I have referred him to someone else to deal with these ethical, and not medical, problems? To whom? Professors of moral philosophy? Perhaps,

but they never see patients. A clergyman? Perhaps, but it is unthinkable that a Communist like Karlsson would have turned to a clergyman for guidance.

Where, then, could he have looked for unbiased advice? Maybe any reasonable and experienced person, endowed with common sense, could have guided Karlsson. But he chose to speak with me, for reasons which people often give for seeing a physician rather than a pastor or friend. The physician may be personally prejudiced, but his guild's ethic promotes at least a greater neutrality than would be encountered in a clergyman; he has no predictable answer; and he must protect the confidentiality of his patient.

Certainly, I had no specific expertise in Karlsson's case: my experience was limited and even my reasonableness was questionable. Yet as Karlsson's physician I had his trust. I think I was right to discuss with him his nonmedical problems—indeed, had I not constrained myself so sharply I might have made a better judgment about his best interests.

The main task of the physician is the practice of medicine, and the medical model should not be overextended. Nevertheless, in certain cases physicians should dare to stretch the bounds of their proper sphere and enter what is, strictly speaking, a nonprofessional relationship with their patients.

There are dangers in this approach: certainly such a relationship must not interfere with the patient's ability to secure other, possibly more useful, forms of professional help. The trust entailed in the patient-physician relationship, the prestige of the medical profession, transference reactions—all these present opportunities for misuse. A physician must be wary of mixing his professional role and his extraprofessional efforts to advise others, lest he benevolently seduce patients into taking up problems about which he can offer no help, whether professional or simply human. To do this is to mislead patients, to create false hopes, and possibly to exacerbate the original problems.

The traditional close relationship between doctor and patient must be safeguarded. But the paternalistic and individualist character of that relationship is no longer either possible or desirable. Patients, as well as physicians, must recognize this change: what is being lost should be compensated for by increased patient participation in and responsibility for treatment. Once that is accomplished, I see no reason why the physician's professional role should disallow treatment of ethical, political, and religious issues. A physician who is aware of his assumptions and prejudices and has learned to discuss openly value questions, as well as his own views, with his patients runs no great risk of uncontrolled or unjust influence on them.

COMMENTARY

by LAURENCE B. McCULLOUGH

At first glance this case seems straightforward enough. Having been sustained throughout his career by the Communist party, Kalle Karlsson was torn between remaining an active Communist and abandoning the party altogether. The resolution of this conflict was too great a burden, and Karlsson's guilt soon crushed him. He was disabled to the point where he was no longer in control of his life. Medical intervention cured Karlsson's depression, but what was the psychiatrist now to do for this unhappy man? The psychiatrist will encounter at least two obstacles as he tries to answer this question.

The first of these obstacles is the temptation to paternalism: designing treatment to disrupt Karlsson's earlier choice to be a Communist and, instead, to make him into, say, a good conservative. This course of action would be justified by pointing out that it was in Karlsson's best interests to become a conservative. After all, had not his life as a Communist only made him miserable and unhappy?

Psychiatric treatment, one might say, is meant to solve personal problems. What was Karlsson's problem? He had been formed and nurtured in his earlier years and later career by the Communist party. He had grown complacent and had subsequently become wretched by his failure to act according to the dictates of the party, now internalized as his conscience. In short, he faced a crisis of moral responsibility.

If the psychiatrist treating Karlsson were to "convert" him, he would likely claim that it was better for him to abandon the Communist cause, and so be free of his guilt. Yet Karlsson's entire life stands as an expression of his will.

To invoke a conception of Karlsson's best interests that directly counters the testimony of his life demands some more compelling grounds than are provided here, some stronger evidence that his integrity might be better served by something other than a return to his political commitment.

The second obstacle the psychiatrist must face is that the temptation to paternalism is strengthened by the "disease model" of conditions like Karlsson's. On this view guilt is taken to be the enemy (and not an ally), a condition to be eliminated. Instead of aiding Karlsson to face his burden of failed responsibility, the psychiatrist might seek to relieve him of it altogether. Karlsson's debt to the party, then, would become a medical disorder, and not a case of moral weakness. His crisis would thereby be transformed from a test of his will to an instance of a psychiatric disorder, a state he was *caused* to suffer. But Karlsson's crisis was initially a moral one, the result of free choice. *Later*, when his burden of failed responsibility overcame him, he developed a medical problem. The psychiatric model of Karlsson's condition, however, may well fail to distinguish these two crises. Indeed, in making guilt the object of treatment, it would appear to conflate those crises.

It is not difficult, then, to see how following the medical model increases the likelihood of taking the relief of guilt to be in Karlsson's best interests, while from the *moral* point of view, such an approach would *not*

be in his best interests. It would deprive him of a crucial opportunity to strengthen and affirm his moral character as a good Communist, by taking up the burden of responsibility he had freely incurred.

This case, then, serves as a good example of how psychiatric disease models can encroach upon and even appropriate, if unwittingly, moral categories. Psychiatric medicine and its practitioners may as a consequence be blinded by medical models to the best interests of patients who must face *moral* crises. On this view, moral crises are seen as not of our own making, but thrust upon us by external forces; they are to be avoided and the patient relieved of their burden. This, however, denies the core of the moral life: the exercise of freedom and responsibility for one's free choices. Acting freely, of course, may have painful consequences, as Karlsson discovered. Psychiatric medicine should assist us to bear the responsibility for those consequences with grace and stability, and not urge us pell-mell to flee from them. The best course of treatment in cases like Karlsson's would be to bring the patient to face his crisis squarely, so that he can meet his responsibility, even if in so doing he must bear a burden of guilt.

The Race for Medical School: An R_x for Speed

John Martin, an undergraduate student at a highly selective liberal arts college, enters the office of his physician, Harold Jones. The two have established a good personal relationship during the previous few years based on Mr. Martin's experience as a pre-med student and his active interest (which he has passed on to Dr. Jones) in the problems of medical ethics.

Despite their good relationship the request that the student makes surprises the doctor. In two months Mr. Martin will be taking the Medical College Admissions Test (MCAT). Since relatively small alterations in his score would significantly alter his chances for admission, he asks Dr. Jones to supply him with amphetamines to aid in maximizing his performance. He tells Dr. Jones that a careful study of the scientific literature provides strongly suggestive although not conclusive evidence that his performance would be enhanced (especially on the quantitative section) by "treatment" of this kind.

The student requests two doses of the drug. He intends to take one dose prior to the test to acclimate himself to its effects and to discover if he is one of the rare individuals to react unfavorably. The second dose would then be taken immediately prior to the test.

Drawing on their previous discussions of medical ethics, Mr. Martin presents an array of arguments in support of his request, including appeals to what Dr. Jones knows to be several of Mr. Martin's sincerely held positions on medical ethical questions.

Dr. Jones has no fears for his own welfare in this case. He trusts John completely in that respect. He also considers him to be exceptionally mature; he therefore feels strongly that supplying the drug in this case would by no means start the student on the road to drug dependence. Finally, the doctor is well aware that a college student can easily obtain amphetamines illegally.

What should Dr. Jones do?

—Lewis Silverman

COMMENTARY

by RONALD A. CARSON

Competition for admission to medical school continues at a fever pitch, a situation that is widely noted and lamented. Students are often victimized by this process. Many survive unscathed; some are made bitter, still others become clever. It is my impression that John Martin has tacitly decided to outsmart the admissions process. There is, to be sure, good humor in the prospect of this young man running the gauntlet at high speed. But this is not just a lark. The stakes are in fact quite high, and I think that Mr. Martin is wrong to ask his friend and physician to provide him amphetamines for admittedly nontherapeutic purposes.

The fundamental question posed by the case is not how to help a person who is having difficulty functioning, but whether to assist a superbly functional person improve his chances for entry into medical school (and outscore his unwitting peers on the qualifying test).

There seem to me to be several reasonable arguments against the legitimacy of the request. One might set out from a "naturalist" distrust of drugs generally and argue that maximum performance on the Medical College Admissions Test should be just that and not artificially induced maximum performance. That is, John Martin should not aspire to the best performance he can *contrive* but to the very best he can *muster*. Related to this is the argument that fairness requires that the rules of competition allow each competitor to demonstrate his "raw" ability. To prepare for the exam by reviewing materials and refreshing one's memory is to play by the rules; to prepare by taking amphetamines is to break the rules and take unfair advantage.

Or, one could argue a case for consistency. Whereas there may be nothing intrinsically objectionable about the student's ingesting two doses of amphetamines, he does not, by his own admission, intend to live or practice medicine like that. The burden of justifying these two exceptions thus rest squarely with him. Since competition is a many-runged ladder, John Martin's claim that he intends to engage in these tactics "just this once" is, at best, a curious sleight-of-mind.

One could, I said, make out a case against the legitimacy of the student's request in either one of the above ways. I have chosen neither of them because for me the crux of this case is the character of friendship.

The governing principles in the case are fidelity and propriety. Friendship is characterized by personal affinity, mutual trust, and steadfastness—in a word, fidelity. Friendship requires a discerning of and a respect for the personal "boundaries" established by friends for the necessary purpose of distancing themselves from each other. Friends may criticize but they possess a sound sense of what is appropriate—fitting—in "a good personal relationship." Dr. Jones's expression of surprise suggests that he regards Mr. Martin's request not wrong in a moral sense (he does not question his maturity nor fear for his own welfare) but inappropriate to their relationship. That request constitutes a breach of the bond of fidelity that is the basis of friendship and an intrusion upon the personal boundaries without which friendship cannot endure.

What should Dr. Jones do? He should

inform John Martin that he is taking unfair advantage of a privileged relationship. He should make it clear that, optimally, he (Mr. Martin), a competent adult, is free to control his own body chemistry, but that he is not at liberty to enlist his physician-friend in altering that body chemistry for the purpose of scoring a few extra points on the MCAT. He might also want gently to point out to his young friend that, as an undergraduate at a highly selective liberal arts college, odds are he'll score in the high 600s on the exam stone-cold sober.

COMMENTARY

by ROBERT M. VEATCH

Although the case is set in terms of the dilemma for the physician who receives an unexpected request for a prescription, a prior question must be faced by both Mr. Martin and Dr. Jones. Is the use of amphetamines for the purpose of maximizing performance on an important test justifiable?

The current mood is, often unquestioningly, opposed to drug use: "Pill poppers" are stereotyped as unstable individuals, victims of the drug industry, escapists, or individuals craving a technological fix. They may of course be all of these, but not necessarily. Both pro- and anti-drug use camps may be oversimplifying the questions of values and beliefs at stake. The glorifiers of the natural seem to take the view that any pharmacological tampering is an assault on the mysteries of nature. Those defending drug use accuse the opponents of being puritanical.

I see nothing wrong with the puritan ethic, but it does not seem to me to lead to blanket opposition to drug use. In fact I would see John Martin's drug use to be consistent with that ethic. His goal is maximum performance, and he is willing to compromise all other subsidiary values to achieve that goal. Certainly this secular puritanism can be overdone, but it hardly seems to be the greatest of moral outrages. I fail to see anything grossly wrong with the decision to try the drug. The decision was made carefully after considerable reflection and study of possible risks. The risks of addiction and of idiosyncratic effect have been explored. The position he has taken is well within the realm of plausibility that should be tolerated.

Dr. Jones' problem is rather different. He could have objected to the value orientation of his patient/friend, but apparently does not. He could apply the traditional Hippocratic dictum that the physician's duty is to do what he thinks will benefit his patient. He seems to be led to the conclusion that the potential benefits are great, the risks small, the risks of alternative courses of action greater, and the values underlying the decision acceptable, if not noble. If he were truly Hippocratic under these circumstances, he would have to decide to provide the amphetamines.

There is a problem, however. It is to be hoped that his judgment will not be based solely on what he thinks will be most beneficial. He might, for instance, be sufficiently committed to patient self-determination that he would be willing to cooperate in some medical procedures, provided they do not violate his conscience too radically, even if he did not consider them most beneficial. That added ethical consideration would merely solidify the conclusion that he should write the prescription. He should also cope with the fact that many others seem to consider this use unwise or harmful. One plausible reason for a physician to reconsider doing what he thinks will benefit a patient is the overwhelming consensus of others that it would not be the most beneficial course on balance.

In the United States there are very limited approved uses for amphetamines: hyperkinesis and narcolepsy. Clearly John Martin has neither syndrome. Should then the physician violate the law to fulfill his Hippocratic obligation? Physicians, like revolutionaries, may see themselves as above the law, as responding to a "higher calling." I have always respected the individual who acts on conscience, committing civil disobedience in responding to a higher law.

There is also, however, a general duty of citizens who choose to continue to live within the civil authority of the state, accepting its privileges and responsibilities to obey the civil law. The citizen should engage in civil disobedience only after reading Socrates and Thoreau and when overwhelming moral force of conscience compels one to say, "Here I stand, I can do no other," to do so publicly, and to be prepared to take the consequences of one's actions.

This seems hardly to be a case on which Dr. Jones should take such a stand. The ethic of the duty to live within the law is an ethic of fidelity to one's civil community. It may be fundamentally non-Hippocratic, but it seems to me to be the one moral basis upon which Dr. Jones should refuse to cooperate with John Martin.

4

Death and Dying

Active Euthanasia with Parental Consent

Andrea was a nine-year-old girl who had been diagnosed as having cystic fibrosis at the age of thirteen months. Since then she had been hospitalized twelve times, eight times during the last year.

When admitted for the last time she was already receiving an experimental antibiotic, which was being administered in an attempt to control a resistant pneumonia superimposed on severely damaged lungs, a result of her underlying disease. She was at that time a severely ill, emaciated child with moderately labored breathing. She seemed to have no interest in her environment and refused to communicate with anyone but her mother.

Because of the severity of the child's illness and because the parents had accurately perceived that the experimental antibiotic was a "last ditch" attempt to control her pulmonary infection, the physicians discussed with the parents their perception of "extreme medical measure" and the significance of a "No Code" order. The parents indicated that in the event of a cardiac or respiratory arrest, they did not want their child to be resuscitated and the appropriate "No Code" order was written. The child was not involved in these conversations or subsequent decision making, nor had the mother previously been able to answer her daughter's questions about death and dying.

As the child's condition continued to decline, the parents asked how much longer she would live and how she would die. At one point the father said: "Watching your own child die is worse than dying yourself." This comment led to a discussion of active euthanasia utilizing intravenous potassium chloride or a similar drug. The physicians pointed out that no matter how hopeless a situation or the amount of suffering that the patient and family were enduring, the law prohibits the active taking of a patient's life. They refused to consider this option.

The following day Andrea's heart began to fail. Her condition became progressively worse, and she died approximately 48 hours later. During these last two days her parents were appalled by her grotesque appearance, with "eyes bulged out like a frog," and were in great despair because of her steadily deteriorating condition. They felt helpless and impotent to alleviate their daughter's distress. Medical treatment was continued to the end, and no measures were taken to hasten Andrea's death.

Approximately two months after her death, the mother was asked if she would still have given permission for active euthanasia if she had been offered that option. She replied, "Yes."

Should active euthanasia be permitted to spare the patient and family from suffering when death is inevitable?

—Hunter C. Leake III

COMMENTARY

by JAMES RACHELS

Active euthanasia is illegal; is it immoral as well? The American Medical Association says that it is. In its 1977 policy statement on the physician and the dying patient, the AMA condemns mercy killing as "contrary to the most fundamental measures of human value and worth."

The case presented here might cause us to doubt that judgment. Exactly what are the "fundamental measures of human value and worth" which require that Andrea suffer a forty-eight-hour period of dying, with her eyes bulging like a frog's? Her parents saw little value or worth in that sort of death. They favored active euthanasia because they thought it better for the child. If their judgment was reasonable—if in fact those forty-eight hours did Andrea no good—then insofar as medical policy should benefit patients, it should not absolutely exclude active euthanasia.

Traditional medical ethics insists upon a sharp distinction between killing and letting die. After condemning mercy killing, the AMA statement goes on to say that allowing patients to die by ceasing treatment is in some circumstances all right. Accordingly, Andrea was allowed to die but not killed. Yet upon analysis this distinction seems to have little real importance. From the point of view of the patient, the outcome is the same no matter whether she is killed or allowed to die: either way, she ends up dead. When in particular cases there is a practical difference between the two, the difference most often is that killing involves less suffering. In this respect Andrea's case is typical.

The refusal to consider active euthanasia, while at the same time allowing death by stopping treatment, also seems to involve a kind of practical inconsistency. The inconsistency emerges when we consider *why* the physicians were willing to allow death, when they could have fought it off for a while longer. Presumably it was because they felt that prolonging Andrea's life was pointless—that she would be better off not going through the longer process of dying that would take place if they stretched things out to the bitter end. But, having made *that* judgment, why should the no-code designation be preferred over the injection? If it was pointless for her to endure, say, a four-day period of dying, why should we choose a course that requires her to endure a two-day period of dying? Active euthanasia seems more consistent with the reasoning that motivates us not to prolong life in the first place.

We are taught from childhood that the rule against killing is among the most serious moral prohibitions, just as we are taught that the special task of medicine is to protect life. It is little wonder, then, that many people find mercy killing hard to accept. However, a sound moral education also includes the instruction that letting people die is wrong: thus physicians normally do *not* let their patients die when they are sick. In this case the physicians allow Andrea to die because the usual reasons for keeping people alive do not apply. But neither do the usual reasons against killing apply. The reason why killing is wrong is that, normally, to kill someone is to destroy a life, not merely in the biological sense, but in the sense of a life as an ongoing human activity. Tragically, Andrea's life in this latter sense was already over, no matter what course of action her physicians had chosen. Moreover, the reason we applaud the physician's commitment to protect life is that protecting one's life is, normally, doing one a great service. Yet in this case it is hard to see how Andrea is served by the refusal to end her life forty-eight hours earlier. On the contrary, it seems to be the parents and not the physicians who represented *her* interests at the end.

The one feature of this case that makes active euthanasia problematic is that the patient herself does not request it. If Andrea were three years old the requirement of consent would not be appropriate; if she were twenty-three, the lack of consent would be enough to stop all discussion. The fact that she is nine makes things more complicated. Children of that age are capable of understanding what it means to die, and it is unfortunate that Andrea's mother had been unable to cope with her daughter's questions. Children old enough to understand should have such situations explained to them, if only because they will figure out what is going on anyway and will need the comfort that calm and sympathetic discussion might bring. But leaving aside the earlier failure of communication, it is a different issue whether now, when death is imminent, Andrea should be asked whether she prefers an injection. My own judgment is that it would not be wise. Nothing would be gained by putting such a question to her, and it might very well make her dying all the more miserable. The consent of her parents, who obviously love her and want what is best for her, is enough. If this is doubted, it might help to ask why we are willing to issue a no-code order without first securing her consent. If one is permissible, why not the other?

COMMENTARY

by PHILIPPA FOOT

In the description of this case it is assumed, quite reasonably, that it was right to allow the patient to die rather than to start resuscitation procedures when her heart began to fail. But given the hopelessness of her condition, Andrea's parents would, it appears, have chosen that measures be taken to kill the child at an earlier time. Legally it was impossible for the doctors to give a lethal injection: would it also have been morally wrong?

The decision depends on the answer to two questions. In the first place, is it morally relevant to distinguish "active" from "passive" euthanasia? Some moral philosophers argue that if it was morally unobjectionable to allow her to die then it must have been similarly unobjectionable to do what the parents desired, since the difference between active and passive—between allowing an independently established sequence to run its course and initiating a new sequence—never affects the morality of what is done. Thus, if Andrea could be allowed to die of the diseases that were slowly killing her, her death could also have been induced earlier by an injection of potassium chloride or some similar drug.

My own view is that this is a serious error. If one may, in particular circumstances, allow a man to die it does not *follow* that one may also kill him, even for his own good. Sometimes, no doubt, where passive euthanasia is justifiable so is the active form, and I do not know what

would be meant by saying here that nevertheless one was "better" or "worse" than the other. It is not, however, always true that the difference between active and passive (so understood) is morally irrelevant. Sometimes it is morally permissible to allow someone to die when it would not be permissible to give him a lethal injection.

When is this distinction morally relevant? Most obviously it is in cases in which rights are in question, and this is because a man's right to noninterference usually extends farther than his right to be cared for. His rights may block our interference in his life; but if we may not intervene to bring a certain result, it does not follow that we may not allow it to come about. We could not, for example, deprive ing away. This conclusion is confirmed by the fact that permission may make all the difference in such a case. The distinction between active and passive is no longer relevant when someone is able to grant us the right to intervene in his life, or at least a man of his property, even for his own good, in many cases in which we would have no obligation to prevent it from blow- not directly relevant as it was before. Thinking only of the morality of the individual action, and so leaving aside such questions as that of the abuse of a practice, one might reasonably say that if someone gives us the right to kill him, for his own good, by seriously consenting to the action, it then makes no moral difference whether we do kill him or rather allow him to die.

That there is a morally relevant difference between active and passive euthanasia seems clear enough when one thinks about the crucial question of rights; and those who deny it seem simply to have misunderstood the position of their opponents. It is, however, hard to know what to say about the treatment of the patient whom we have been asked to discuss, because a second controversial question arises at this point. The case of Andrea and others like her is problematic because she was too young to be able to give valid consent to the measure that would have killed her, and so to give us the right to do what in general we have no right to do without consent. What should we think about active euthanasia in relation to children and mentally incompetent adults?

Should we say, for instance, that machinery might be set up by which guardians (though hardly parents alone) could be held to speak for the patient and to grant on his behalf the permission that a "competent" adult could give us himself? One might believe that although no competent adult could justifiably be the subject of active euthanasia unless he himself had consented to it, others could consent for children and for mentally incompetent adults, or at least for those adults who had never been able to give valid consent. I believe that there would be no decisive objection on grounds of moral principle if it were not for the problem of the possibility of abuse. But in practice there seems to be grave danger that children and noncompetent adults would be "spoken for" by people who were really speaking for relatives, for the medical staff, or for "society," rather than for those whose rights they were supposed to guard.

The reality of the danger is, I think, vividly illustrated by the presentation of Andrea's case. First, very little is said about the one absolutely crucial factor in the situation, namely her state of consciousness and suffering. Second, the possibility is mentioned of giving the injection "to spare the patient and family from suffering" as if the suffering of others was as relevant as that of the patient. And third, much is made of the pain caused to the parents by the alteration to the point of grotesqueness in their daughter's appearance.

Now I do not for a moment want to deny that there may be cases of terrible suffering that can be ended only by death, though the subject of uncontrollable pain is, of course, one on which doctors disagree. Were we sure that active euthanasia would be practiced only where death was clearly much to be desired *for the sake of the patient*, then it could be right to allow it, even for those who had not themselves been able to give consent. But it would be quite another matter to kill such patients for the good of others, labeling it (improperly) euthanasia, and opening the way to programs such as the one instituted by Hitler before he undertook the extermination of the Jews. (See my article, "Euthanasia," *Philosophy and Public Affairs* Winter 1977.) I am not, of course, suggesting that if Andrea had been treated as the parents wanted it would have been a case of this kind; only that the presentation of the case blurs just the distinction that should be emphasized. Moreover, there is something superficial about the thought that weighs the parents' distress at their daughter's appearance in this particular balance. For all the misery of this part of their experience it is not something to be grieved over like the loss of the child or her pain. Nor should we be impressed when we are told, as we sometimes are, that a man is treated in a "dehumanizing" way if he is allowed to become grotesque in appearance before he dies. Death is not normally pretty, and it will be no gain if ugliness in death comes to seem to us intolerable. Would Andrea's parents really have been better able to live with the grief of losing her if they thought that they had ordered the lethal injection partly to spare themselves the pain of seeing her as she would become?

It may be thought that in mentioning such matters, and not thinking only of the case or active euthanasia to put an end to a patient's suffering, I am evading the main issue. This is not true. For when we are considering a practical measure such as the permitting of active euthanasia it is a very important fact that we are apt to think about it in a confused and superficial way. This is one reason why there is so much danger in supporting any kind of active euthanasia, never mind its extension to children and noncompetent adults.

A Demand to Die

Two months after being discharged from three years of military service as a jet pilot, the world of Donald C. exploded in a flash of burning gas. He was then twenty-six years old, unmarried, and a college graduate. An athlete in high school, he loved sports and the outdoors. Rodeos were his special interest, and he performed in them with skill. Upon leaving the military in May, 1973, Donald joined his father's successful real estate business. The two of them had always had a close and warm relationship. On July 25, 1973, they were together, appraising farm land. Without realizing it, they parked their car near a large propane gas transmission line; the line was leaking. Later, when they started their automobile, the ignition of the motor set off a severe and unexpected explosion. Donald, his father, and the surrounding countryside were enveloped in fire. The father died on the way to the hospital, and Donald was admitted in a critical but conscious state. He sustained second- and third-degree burns over sixty-eight percent of his body—mostly third-degree burns. Both eyes were blinded by corneal damage, his ears were mostly destroyed, and he sustained severe burns to his face, upper extremities, body, and legs.

During the next nine months, Donald underwent repeated skin grafting, enucleation of his right eye, and amputation of the distal parts of the fingers on both hands. The left eye was surgically closed in order to protect it from the danger of infection; the cornea was badly scarred and the retina was partially detached. His hands, deformed by contractures, were useless, unsightly stubs. When admitted to the University of Texas Medical Branch Hospitals in April, 1974, the patient had many infected areas on his body and legs. He had to be bathed daily in the Hubbard tank to control infection.

From the day of the accident onward, Donald persistently stated that he did not want to live. Nonetheless, he had continued to accept treatment. Two days after admission to the University hospital, however, he refused to give permission for further corrective surgery on his hands. He became adamant in his insistence that he be allowed to leave the hospital and return home to die—a certain consequence of leaving since only daily tanking could prevent overwhelming infection. The tankings were continued despite his protests. His mother, a thoughtful and courageous woman, was frantic; his surgeons were frustrated and perplexed.

Although calm and rational most of the time, the patient had frequent periods of childlike rage, fear, and tearfulness. He engaged his mother by the hour in arguments regarding his demand to leave the hospital—which, of course, he was physically incapable of doing unless she agreed to take him home by ambulance.

At this juncture, Dr. Robert B. White was asked to see the patient as a psychiatric consultant. Prior to seeing the patient he was given the impression that Donald was irrationally depressed and probably needed to be declared mentally incompetent so that a legal guardian could be appointed to give the necessary permission for further surgery and other treatments. The patient's mother was understandably in favor of his remaining in the hospital. She was deeply concerned about her son's welfare, and the prospect of taking him home to die from pus-covered sores on his body was more than she could bear. She was a deeply religious woman and was also concerned lest her son die without re-accepting the church which he had left some time prior to his burns.

Donald was the eldest of three children. By his family's account, he was an active, assertive, and determined person, who since childhood had tended to set his own course in life. What or whom he liked, he stuck to with loyalty and persistence; what or whom he disliked, he opposed with tenacity. His mother stated, "He always wanted to do things for himself and in his own way." Dr. White soon concluded that the mother's summary was apt. In the course of the first few interviews it was apparent that Donald was a very stubborn and determined man; he was also bright, articulate, logical, and coherent—not by any criterion mentally incompetent. He summarized his position with the statement, "I do not want to go on as a blind and crippled person." Arguments that surgery could restore some degree of useful function to his hands, and perhaps some useful vision to his remaining eye, were of no avail. His determination to leave the hospital was unshakable, and he demanded to see his attorney in order to obtain his release by court order if necessary.

COMMENTARY

by ROBERT B. WHITE

Donald's wish seemed in great measure logical and rational; as my psychiatric duties brought me to know him well, I could not escape the thought that if I were in his position I would feel as he did. I asked two other psychiatric colleagues to see the patient, and they came to the same conclusion. *Should his demand to die be respected?* I found myself in sympathy with his wish to put an end to his pathetic plight. On the other hand, the burden on his mother would be unthinkable if he left the hospital, and none of us who were responsible for his care could bring ourselves to say, "You're discharged; go home and die."

Another question occurred to me as I watched this blind, maimed, and totally helpless man defy and baffle everyone: could his adamant stand be the only way available for him to regain his independence after such a prolonged period of helplessness and total dependence?

Consequently, I decided to assist him in the one area where he did want help—obtaining legal assistance. He obviously had the right to legal recourse, and I told him I would help him obtain it. I also told him that I and the other doctors involved could not accede immediately to his demand to leave; we could not participate in his suicide. Furthermore,

he was, I said, in no condition to leave unless his mother took him home, and that was an unfair burden to place on her. I urged him to have the surgery; then, when he was able to be up and about, he could take his own life if he wished without forcing others to arrange his death.

But Donald remained adamant, and the patient, his attorney, and I had several conferences. Finally, the attorney reluctantly agreed to represent the patient in court. The patient and I agreed that if the court ruled that he had the right to refuse further treatment, the life-sustaining daily trips to the Hubbard tank and all other life-sustaining treatment would be stopped. If he wished, he could remain in the hospital in order to be kept as free of pain as possible until he died.

Had Donald been burned a few years ago, before our increasingly exquisite medical and surgical technology became available, none of the moral, humanitarian, medical, or legal questions his case raised would have had time to occur; he would simply have died. But Donald lived, and never lost his courage or tenacity. He has imposed upon us the responsibility to explore the questions he has asked. On one occasion Donald put the matter very bluntly: "What gives a physician the right to keep alive a patient who wants to die?"

As we increase our ability to sustain life in a wrecked body we must find ways to assess the wishes of the person in that body as accurately as we assess the viability of his organs. We can no longer blindly hold to our instinctive tendency to regard death as an adversary to be defeated at any price. Nor must we accept immediately and at face value a patient's demand to be allowed to die. That demand may often be his only way to assert his will in the face of our unyielding determination to defeat death. The problem is relatively simple when brain death has occurred or when a patient refuses surgery for cancer. But what of the patient who has entered willingly on a prolonged and difficult course of treatment, and then, at the point at which he will obviously survive if the treatment is continued, decides that he does not want further treatment because he cannot tolerate the kind of future life that his injuries or illness will impose upon him?

The outcome of Donald's case does not resolve these questions but it should add to the depth of our reflections. Having won his point, having asserted his will, having thus found a way to counteract his months of total helplessness, Donald suddenly agreed to continue the treatment and to have the surgery on his hands. He remained in the hospital for five more months until medically ready to return home. In the six months since he left, Donald has regained a considerable measure of self-sufficiency. Although still blind, he will soon have surgery on his eye, and it is hoped some degree of useful vision will be restored. He feeds himself, can walk as far as half a mile, and has become an enthusiastic operator of a Citizens Band radio. When I told him of my wish to publish this case report, he agreed, and stated that he had been thinking of writing a paper about his remarkable experiences.

COMMENTARY

by H. TRISTRAM ENGELHARDT, JR.

This case raises a fundamental moral issue: how can one treat another person as free while still looking out for his best interests (even over his objections)? The issue is one of the bounds and legitimacy of paternalism. Paternalistic interventions are fairly commonplace in society: motorcyclists are required to wear helmets, no one may sell himself into slavery, etc. In such cases society chooses to intervene to maintain the moral agency of individuals so that their agency will not be terminated in death or in slavery. Society chooses in the purported best interest (i.e., to preserve the condition of self-determination itself—freedom) of the would-be reckless motorcyclist or slave. Or, in the paradigmatic case of paternalism, the choice by parents for their children is justifiable in that at a future time as adults, the children will say that their parents chose in their best interests (as opposed to the parents simply using their children for their own interests). That is, the paternalism involved in surrogate consent can be justified if the individual himself cannot choose, and one chooses in that individual's best interest so that if that person were (or is in the future) able to choose, he or she would (will) agree with the choice that has been made in his or her behalf.

Thus, one can justify treating a burned patient when first admitted even if that person protested: one might argue that the individual was not able to choose freely because of the pain and serious impact of the circumstances, and that by treating initially one gave the individual a reasonable chance to choose freely in the future. One would interpret the patient to be temporarily incompetent and have someone decide in his behalf. But once that initial time has past, and once the patient is reasonably able to choose, should one respect a patient's request to refuse life-saving therapy even if one has good reason to believe that later the patient might change his or her mind? This is the problem that this case presents.

Yet, what are the alternatives which are morally open: (1) to compel treatment, (2) at once to cease treatment, or (3) to try to convince the patient to persist, but if the patient does not agree, then to stop therapy. Simply to compel treatment is not to acknowledge the patient as a free agent (i.e., to vitiate the concept of *consent* itself), and simply to stop therapy at once may abandon the patient to the exigencies of unjustified despair. The third alternative recognizes the two values to be preserved in this situation: the freedom of the patient and the physician's commitment to preserve the life of persons.

But in the end, individuals, when able, must be allowed to decide their own destiny, even that of death. When the patient decides that the future quality of life open to him is not worth the investment of pain and suffering to attain that future quality of life, that is a decision proper to the patient. Such is the case *even if* one had good reasons to believe that once the patient attained that future state he would be content to live; one would have unjustifiably forced an investment of pain that was not agreed to. Of course, there are no easy answers. Physicians should not abandon patients when momentary pain over-

whelms them; physicians should seek to gain consent for therapy. But when the patient who is able to give free consent does not, the moral issue is over. A society that will allow persons to climb dangerous mountains or do daredevil stunts with cars has no consistent grounds for paternalistic intervention here. Further, unlike the case of the motorcyclist or the would-be slave, in this case one would force unchosen pain and suffering on another in the name of their best interests, but in circumstances where their best interests are far from clear. That is, even if such paternalistic intervention may be justifiable in some cases (an issue which is different from the paternalism of surrogate decision-making, and which I will not contest at this point), it is dubious here, for the patient's choice is not a capricious risking of the basis of free action, but a deliberate choice to avoid considerable hardship. Further, it is a uniquely intimate choice concerning the quality of life: the amount of pain which is worth suffering for a goal. Moreover, it is, unlike the would-be slave's choice, a choice which affirms freedom on a substantial point—the quality of one's life.

In short, one must be willing, as a price for recognizing the freedom of others, to live with the consequences of that freedom: some persons will make choices that they would regret were they to live longer. But humans are not only free beings, but temporal beings, and the freedom that is actual is that of the present. Competent adults should be allowed to make tragic decisions, if nowhere else, at least concerning what quality of life justifies the pain and suffering of continued living. It is not medicine's responsibility to prevent tragedies by denying freedom, for that would be the greater tragedy.

The Nurse and Orders Not To Resuscitate

Mrs. R. is in her mid-forties and has multiple sclerosis. Her two teenage daughters live with her. Mr. R., a middle-management executive in a local firm, divorced her five years ago.

Mrs. R. often comes into the emergency room of the local community hospital for treatment of acute episodes of asthma. The physician has ordered "no code" if Mrs. R. suffers a cardiac arrest during an acute asthma episode, that is, she should not be resuscitated. (Hospitals have various signals, or codes, by which they call a resuscitation team to a particular room over the loudspeaker system without alarming other patients and visitors.)

As far as the nurses know, the physician made this decision without discussing it with the patient or her family. One nurse is terribly upset because this decision conflicts strongly with her professional values, even though she herself has said on several occasions that Mrs. R's home situation is "intolerable" and that she "certainly wouldn't want to live under those circumstances." None of the nurses has heard Mrs. R. express any similar feelings about her situation, even though she usually seems depressed when she comes into the emergency room.

What, if anything, should the nurse do before Mrs. R. comes into the emergency room? Does the nurse have an obligation to intervene rather than just "praying" that Mrs. R. "doesn't come in on my shift"?

—Mila Aroskar

COMMENTARY

by M. JOSEPHINE FLAHERTY

Professional nursing behavior is directed by the Code for Nurses and its imperative of integrity. The code requires at least that, no matter what the cost, the nurse do what he or she believes to be right, be committed to protecting the public and the client, be accountable *for* his or her professional behavior rather than simply accountable *to* someone in a hierarchy, and cooperate with nursing colleagues and others to promote community and national efforts to meet the health needs of the public.

The nursing profession supports statutory regulation of nursing practice that promotes high standards of competence, expects nurses to be available to clients and diligent in their care, and demands that nurses appreciate and accept clients' values, including their decisions to comply or not with proposed medical and nursing care plans.

In this case, the data indicate that although the client has health and family problems, she is coping with daily living. Her visits to the emergency room show that she is seeking and accepting assistance from members of the health care system. Nursing action indicated here includes doing for the patient what she cannot do for herself during crisis periods, taking action to enhance the patient's ability to manage on her own, improving her family's ability to assist her, and developing new strategies for dealing with the effects of the asthma, multiple sclerosis, and other problems.

The case suggests that the physician may have decided on his own that NO CODE be called in the event of a cardiac arrest during an acute asthma episode, without discussing it with the patient. However, there is no empirical evidence to support this supposition, and the nurse cannot assume that the patient's and the physician's views differ.

Although one nurse is of the opinion that the patient's situation is "intolerable," that nurse has no concrete evidence that the patient shares this opinion. Clearly, the nurse should take both preparative measures (anticipatory action before Mrs. R. returns to the emergency room) and reactive measures (in response to Mrs. R.'s reappearance in the emergency room).

The nurse should find out more about Mrs. R. from records, from health care and other appropriate workers, including the physician who ordered the NO CODE and from Mrs. R. and her family themselves. The apparent absence of community health nursing care should be investigated. The lack of information about specific factors that are associated with Mrs. R's acute asthma attacks is also puzzling. All these sources of information should help the nurse understand the rationale for the NO CODE order and plan nursing and other care for Mrs. R, possibly including a referral to outside individuals and agencies.

The fact that one nurse has values that are in conflict with an order that has been written for Mrs. R. suggests that either the order is not congruent with hospital policy or practice or that the nurse is employed in a situation that is not consistent with her values. Either situation would be professionally unacceptable and would require action by the hospital, the nurse or both. The nurse's obligation to "intervene" rather than just "pray" is clear; the nature of the intervention (attempting to change the practice in this instance if it conflicts with hospital policy, or resigning from a position that is morally unacceptable to her) would depend on the information that is obtained about this situation.

When the patient returns to the emergency room, the nurse will be obliged to practice nursing according to her professional standards and values, both of which must take into account the ethical implications of nursing intervention in this patient's particular situation.

The moral principles involved include the nurse's commitment to a high standard of nursing behavior that will enhance a patient's ability to cope effectively with her situation (that could involve helping her toward a peaceful death), to ensuring that the patient gives informed consent for any treatment, to providing for and respecting the patient's right to self-

determination of care (that might include a decision to refuse care), to practicing with integrity and being accountable for her own professional behavior, and to safeguarding the client and the public when health care and safety are affected by the incompetent, unethical, or illegal practice of any person.

COMMENTARY

by JAMES M. SMITH

Before suggesting an approach to the problems presented by this case, I want to describe the way of conceiving of nursing as a profession on which my approach is based. On this conception nursing is defined as a profession by the shared tasks and goals of its members. The performance of these tasks will require the possession of certain skills, capacities, and dispositions.

The code of ethics is the public articulation of those characteristic attitudes and dispositions which are central to being a good nurse: it tells the world (and reminds the profession) what sorts of people the professionals are or aspire to be. The underlying view of ethics here regards the central question to be not, "What sorts of actions should we take?" but "What kinds of persons ought we to be?" Agreement on this determines not rules but basic attitudes, perceptions of situations and dispositions to act.

We would not expect the code to provide answers to ethical problems, but only to indicate the kinds of considerations appropriate to reaching a solution. The most important of these considerations, the foundation of the code, is the health of the patient. The primary obligations of the nurse are to patients, not physicians. When there are obligations to the physician or the necessity for subordination arises, it is because those obligations and that subordination are required by the common task. At the same time, no obligation to the physician can survive a conflict with the obligation to the patient. What needs to be developed is a collegial view in which each member of the health care team recognizes a distinctive obligation to foster the health of the patient and regards every other member of the team not as a superior or inferior, but as a source of different information, perspectives, and attitudes.

The problem before us, then, is how one best fulfills the obligation to the patient. Since that is a continuing obligation, it is not only Mrs. R., but future patients in similar circumstances who must be considered. Thus, there are at least three questions that the nurse must consider.

1. What is proper in this case?
2. What ought hospital policy to be?
3. How ought policy be made?

The first step in answering any of these questions is getting more information. In the case of Mrs. R., the nurses do not know enough about the physician's order to take any action. At the same time, some of the information provided is irrelevant. Whether the nurse would want to live in Mrs. R's circumstances gives us no help in determining whether Mrs. R. wants to live in them. It is the answer to that question which determines how the nurses ought to act. Likewise, it is what Mrs. R. thinks about her family life that is crucial, not what others may think.

Before Mrs. R. comes into the emergency room again, the nurse ought to find out whether she has made an informed request not to be resuscitated if she has a cardiac arrest. If she has, that seems to me to justify the NO CODE designation, so long as the nurses are aware that she may change her mind. If Mrs. R. has not made such a request, then the nurse should try to get the NO CODE designation removed until her wishes are determined. (I emphasize that what is required here is not merely consent to a proposal, but a legitimate request. That is, I recognize both a higher and a more complex standard than consent. But in this context—emergency care of a patient coming to the hospital on her own initiative—nothing less would be adequate.)

At the same time, the nurse should try to get hospital policy established or clarified so that such designations are not made without patient requests. Finally, the nurse should help to establish an adequate and well-understood mechanism for determining patient wishes in such matters. Such a mechanism should involve all members of the team.

Should Mrs. R. be admitted to the emergency room before her wishes have been determined, the nurse should ignore the NO CODE designation and solicit the aid of the other health care personnel in giving Mrs. R. the same treatment that would be given routinely to any other patient with her history.

What I have suggested the nurse ought to do is what I would also suggest anyone ought to do with the same knowledge and the same access to hospital policy-making. The special role of the nurse arises out of two general facts: (1) The nurse does have the knowledge, not only of medicine but of the day-to-day operation of the hospital, which only the rare lay person has. Such special capacities usually confer extra responsibilities, and they do in this case as well. (2) While anyone with the nurse's knowledge ought to do these things, the nurse has an obligation to do them, that is, the nurse has an additional ground for intervention arising precisely out of membership in the profession.

From the public point of view, a major reason for recognizing a profession by giving special weight to professional codes or oaths, financial support to professional activities, and licensure to its members is that it helps to establish and maintain a group of persons who have special reasons for acting in certain ways. From the professionals' point of view, the obligations that go with being a part of the profession rest as permanent weights in the scale of judgment, never to be ignored even when, in cases of tragic conflict, they are outweighed.

Nurturing a Defective Newborn

Baby Girl S was born at a small community hospital, four weeks prematurely, after an uncomplicated pregnancy. At birth the baby breathed spontaneously, but shortly thereafter had an apneic episode in which respiration stopped, and oxygen was required. She also had unusual face and hands and showed little spontaneous motor activity. For these reasons she was transferred to a neonatal intensive care unit. Physical examination showed findings consistent with trisomy 18, a serious genetic defect. The infant continued to have occasional episodes of apnea which over the next twenty-four hours became sufficiently severe so that respirator assistance was considered. A heart murmur was noted and signs of early heart failure (normally treated with a variety of medications) became evident.

Mr. and Mrs. S came to the center thirty-six hours after the birth, having been told that Baby S had multiple birth defects. They met with the pediatrician and geneticist caring for the baby. The infant's primary problem was explained (a chromosomal "accident" resulting in extra genetic material in all of the infant's cells, with diverse manifestations), the immediate difficulties outlined (short periods where the infant "forgot" to breath, and a heart defect which was probably an opening between the major artery to the body and the large artery to the lungs, with resultant heart failure), the child's abnormal features described (small size, unusual facial features, and deformed hands), and the long-term outlook explored (profound retardation with very high probability of death within the first year).

Within the next day or two decisions will need to be made:

1. Should resuscitative efforts be continued when the baby 'forgets' to breath?

2. Should a respirator be used if that becomes necessary to maintain the baby's life?

3. Should medication to control the potentially life-threatening heart failure be instituted?

4. Should other routine care be given?

Before these decisions are made, should the parents see the baby? Should the physician encourage or discourage them in touching and holding the baby?

COMMENTARY

by RICHARD M. PAULI

Questions about resuscitation, medication, and allowing to die seem appropriate questions to ask in the case of Baby S. This baby has, with any treatment, a very limited life expectancy; should it survive, it has very little likelihood of evidencing even the most minimal level of "personhood" (that is, affective interaction with other persons). Since the parents should have primary responsibility for deciding about Baby S, they must be given accurate information about diagnosis and prognosis as well as predictions about the results of alternative courses of action. But another way of "knowing" about their baby is to see and touch her. This information, like the other pieces of data, must be made available to them by others. Therefore the attitude of the physician-counselor about nurturing will inevitably influence their own decision.

The physician-counselor may already have decided what medical care decisions are "preferred." Based on this judgment, he could opt for or against the parents seeing and touching the baby depending on which action he viewed as being most likely to result in accord with his "preferred" decision. That, of course, would be paternalism and deceit. But even if the physician-knows-best strategy is rejected, one is left with a difficult question. Does nurturing or non-nurturing, in itself, determine what decision the parents will make about resuscitation and medical support?

One could posit that all parents who first held and touched their infant would be *unable* to *ever* allow it to die. I don't think this is true for most parents. For example, decisions about adult incompetents are often made by family with a nurturing commitment of many years duration, and this is held to be the best way of "assuring loving solicitude for the patient" (the Quinlan case is a good example).

On the other hand, the horror of physical deformity might be anticipated to produce the opposite effect. The loving care evidenced by families with surviving but severely defective children indicates that this need not be an inevitable consequence.

The tension for the physician-counselor in the case of Baby S is the conflict between an active and compassionate concern to minimize the suffering (through overwhelming guilt) of the parents, and the more passive responsibility to allow them to act autonomously. The physician's goal of minimizing parental suffering may be misplaced. Given the opportunity to nurture their defective child, parents will need to be supported through the guilt and grieving following a decision to withhold care, just as a family who elects to treat such a baby will require personal and community support. But attempts to allay their suffering by discouraging or refusing to let them see their baby is to engage in another form of paternal deception.

An informed decision requires accurate information, which we may assume the parents received in the case described. Does a knowledgable decision require more than accurate information? Perhaps well-considered choice *requires* experiential nurturing and a special kind of caring.

I think this other way of "knowing" is beneficial in making truly informed decisions, is a parental right, and is the best safeguard against arbitrary or frivolous

decisions. The physician-counselor's role, then, is to encourage independence and autonomy. He should allow the parents themselves to decide whether to touch and hold the baby, but should encourage them to do so. Our aim should not be easy choices, but real ones.

COMMENTARY

by ERIC J. CASSELL

The birth of this child is a tragedy. No matter what decision is made, or whether the child lives or dies, sorrow and suffering will follow. Therefore, there are two immediate problems: first, to make a decision about treatment and second, to minimize pain and suffering, because such relief is a necessary and legitimate object of medicine.

There are two alternative decisions to be made about her care. Either the infant should be permitted to die from the complications of her genetic defect and given care that will comfort her and relieve her suffering; or she should be kept alive until, beyond the limits of technological rescue, she ultimately dies, usually, we are told, within a year. If she is to be kept alive, the tools to be used—respirators, cardiac drugs, resuscitation—are merely technical details.

The case offers four alternative treatment levels, suggesting some ambivalence in the medical staff. Physicians may say, for example, "I believe she should be kept alive, but only if resuscitation for apnea is sufficient," or "only if therapy for heart failure is sufficient." This ambivalence makes the baby's failure to survive beyond a certain level of technological support the factor that determines outcome. Such decisions merely extend the wheel of fortune from conception into the neonatal intensive care unit and seemingly remove human agency—an understandable strategy, but an illusion nonetheless.

The parents have two choices. Either life is to be saved at all costs, or the decision to treat the baby is based on the infant's individual characteristics. If the parents believe life must be preserved at all costs, then their decision to treat is obvious. We would all sympathize with them and should do what is necessary to minimize their pain whether the infant survives or dies.

But if the decision is to be made on the basis of what the infant will become—her quality of life, her ultimate length of survival, economics, their ideas about parenthood, the effect on siblings or other family members, and future childbearing—then clear thinking and as much information as possible will be necessary. Clear thinking is the ability to weigh the evidence and the sets of competing needs and feelings as objectively as possible—to sort out wishes and desires from the facts of this infant's existence now and in the future.

This kind of thinking may be difficult for the mother who has given birth, just three days earlier, to a child that probably bitterly disappoints her nine months of dreams and wishes. Clear thinking will be made even harder by the inevitable feelings of guilt that accompany such a birth. The mother will wonder whether she did something to bring on the defects. Indeed, it is often easier to accept blame and guilt than to accept one's helplessness in the face of a capricious fate.

Now we come to the more pernicious question. Should the parents be encouraged to nurture the child—to touch her and to hold her—before making their decision?

If their decision is to save her life at all costs, what harm could come from *not* nurturing? The child will not lack such attention in the intensive care unit where nurses will hold and fondle her without the aversion that the inexperienced first feel with a defective child. What good would come from the physician *encouraging* the parents to hold and touch the infant before making the decision? They could ask to do so if they wished.

If the decision is to be based on a careful weighing of the baby's individual characteristics and the therapeutic possibilities, I cannot conceive how nurturing would clarify the mother's painful thinking or provide her with more "information." If the child lives there will be time enough for nurturance.

And if the child dies? Recent research confirms what even the most primitive people know: the bonding of parent and child occurs through the mother's nurturance and the child's response. If an infant is adopted at birth and after a period the biological mother wants the child returned, we feel sympathy for the adopting parents. Why? Because nurturing experience has formed a bond between the parents and their adopted child, so that the loss of the child is not merely the loss of a desirable object, but the loss of a loved one.

Why do pediatricians sometimes *want* the parents with newborns like Baby S to nurture the child? Does the physician wish to teach them, starting here, how to be good parents? Or is there possibly something punitive in encouraging the parent to touch and hold? Does the staff share the magical beliefs on which the parents' feelings of guilt are based? Nurturing this infant will not change her defects or the conditions upon which a decision must be based. But nurturance and the establishment of a bond may make a decision to save the life a selfish one based on the parents' unwillingness to lose a loved one. Furthermore, nurturance will only add to the parents' suffering after her death. Is either a selfish decision or further suffering desirable?

A Condemned Man's Last Wish: Organ Donation & a 'Meaningful' Death

John Evans is a prisoner on Death Row in Holman Prison, Atmore, Alabama. He has been given a stay of execution until the Alabama legislature considers a bill, sponsored by Rep. Edward Robertson, the provisions of which are described in the following letter by Evans:

"My death is imminent. It is my profound wish to be put to death in such a way that my organs can be removed for donation to the vast number of people so urgently in need. Instead of being electrocuted, I want to be put to death by lethal injection.

"My efforts to have this bill passed are in no way an attempt to beat the death penalty. This law is meant only to keep a condemned man's death from being meaningless if he so desires. There are quite a few inmates here on death row who feel just as strongly about this issue as I do.

"If a person is actually going to be executed and legally nothing can be done to halt it, then why shouldn't that person be able to choose his method of dying?

"Furthermore, why shouldn't a person about to be executed be able to exercise his right to stipulate exactly what he wants done with his remains? It would create no extra costs or burden to the state.

"There are no real legal obstacles to such a donation, once a condemned person notarizes and signs the proper papers donating his vital organs for transplant purposes. The bill will stipulate that the choice of donating organs of the body will be left strictly to each individual. The state will have absolutely no influence in the decision.

"I do not ask that a doctor administer the lethal drug. A physician would have no choice but to reject such a practice because it would violate all doctors' code of ethics and the Hippocratic Oath. The proposed bill clearly stipulates that the state executioner will administer the lethal injection.

"The proposed bill allows an execution to take place either in or near a medical facility that can handle the removal of an executed person's vital organs. If the actual execution does not take place in an operating theatre, then the body would be transferred to a medical facility immediately following the execution so that the organs could be removed and preserved for transplantation.

"This proposal is not meant to debate the pros or cons of capital punishment nor is it an effort to cause major legal or professional problems. Neither is it meant to imply that death row be considered as a farm for transplant organs.

"But I do feel that if the death penalty is upheld, and if it comes to the ultimate minute when I am going to be executed without the possibility of a stay, then I should be permitted to choose the method of execution and to donate my organs if I desire."

How should the Alabama legislature vote on Evans' proposed bill?

COMMENTARY

by HUGO ADAM BEDAU

Should a person, as Evans asserts, who cannot lawfully prevent his own execution "be able to choose his method of dying"? The idea cannot be taken literally. Whereas persons who wish to die by an act of suicide do have this *ability* (limited by opportunity and means), persons who are to die by capital punishment do not. Nor do they have the *right* to choose the method of their death. (Suppose the condemned person wanted to be taken up in an airplane and dropped from 10,000 feet into the ocean, or to be put to death by some other bizarre, expensive, risky, or cruel method.)

Nor does a person, as Evans also wants to assert, who is to die by the death penalty have a "right to stipulate exactly what he wants done with his remains." First, the traditional theory of rights (Locke, Blackstone) holds that a condemned murderer forfeits any such right, so that the state has full power to determine the disposition of his corpse. Second, the very idea is too broad. It is doubtful whether anyone has that right, and it is certain that if the condemned person did, it might impose unacceptable duties on the prison authorities (for instance, to cremate the corpse and scatter the ashes from the Atlantic to the Pacific, if the condemned person so "stipulated").

The most that can be said is that a condemned person is under no moral duty *not* to arrange for the lawful post-execution distribution of his bodily organs for the benefit of others, and that there should be no statutory prohibition to prevent him from doing so if he chooses. In terms of moral rights, this is really all that Evans requires, since his basic claim is that it is best, all things considered, for someone who is going to be executed to put his corpse to some useful purpose, so that his death is not "meaningless."

Restated as an issue for the legislature, the question is this: can Alabama most effectively and humanely make the fate of a convicted murder "meaningful," that is, not pointless for his victim, for society in general, and for the convict himself, if it puts him to death in a manner that makes possible the use of his body for organ transplants and if it grants him the legal right to dispose of his body in this manner?

I believe the answer is "No," mainly because an affirmative answer relies on a presupposition that I reject—that capital punishment is necessary. The danger of

Rep. Roberston's bill is that discussing it on its merits treats as a closed issue what for the legislature ought to be a prior open question: are there possibilities for a meaningful *life* for convicted murderers, and not only possibilities for their meaningful *death*? In my view, a painless death humanely inflicted by lethal injection followed by beneficial organ donation as directed by the condemned murderer before his death are mere wrinkles, and not very redeeming or "meaningful" ones, on a barbaric and unnecessary mode of punishment.

However, I must assume that a large majority of the Alabama legislature does not agree with me, in which case they should give serious consideration to the legislation Evans favors. They might reasonably conclude that if a person is certain to die at the hands of society because he murdered an innocent victim, then his death is more meaningful if it occurs in a manner that permits rather than prevents conferring a benefit on others. Even so, however, there are three areas of concern where legislative scrutiny is highly desirable.

Is it really true that death by lethal injection is the best method to facilitate organ donation? I do not know, and I believe further examination of the technical aspects is needed.

The legislature must not discount as easily as Evans does the possibility that "death row" might come to be viewed by society as a "farm for transplant organs." The prospects of a "meaningful" death might encourage trial juries in murder cases to look on their choice of sentence in a new light, because the death sentence had become a necessary condition of affording the convict an opportunity for a "meaningful" death. It might have a similar effect upon prosecutors and commutation authorities. I would regard such developments as morally retrograde, because this legislation would become the source of a new incentive to seek capital indictments and mete out death sentences, and a new disincentive for delaying or nullifying their execution.

It is even possible that the legislature could move toward making organ donation mandatory. Evans contemplates his death as "meaningful" if, in a kind of atonement for his crimes, he dies in a way that enables him to give his organs to others. But why should the legislature care so much about making a death *meaningful* in this way, when it has the power to make it *useful* to others by requiring that a condemned man's body be used for organ donation? Since the desire to make such a death useful and the conviction that the lives of murderers are useless seems to govern the prior legislative decision in favor of capital punishment itself, I see no reason for the legislature to strain at a gnat, having swallowed a camel.

COMMENTARY

by MICHAEL ZEIK

That even a condemned prisoner does not cease to be an end in himself, rather than a mere means to societal ends (an object-lesson to would-be criminals, for example), is confirmed not only by state and federal law (respecting minimal rights of inmates), but also by international agreements, and the UN Declaration of Human Rights. And the considerable publicity given organizations like Amnesty International argues the widespread acceptance of such norms.

The request of the prisoner scheduled to die in Holman Prison—that he be allowed a form of execution enabling the donation of his vital organs to society—should be respected. Granting his request would be congruent with the principle stated above. By acceding to the condemned man's wish—one which adds meaning to his life, and dignity to his death—the laws of the state are carried out, and the community is well-served.

From Plato on, however, moral philosophers have observed that ethical judgements become increasingly difficult as they descend from the purity of abstract principle to the murkiness of concrete application. None of us is excused from the anguish of application; we all necessarily bear on our shoulders the twin burdens of ambiguity and ambivalence.

In this particular case, two levels of doubt occur to me. The first, I think, is easily disposed of; the second, not insoluble, is more difficult.

First, the state law, if amended as the prisoner desires, must cope with the fact that a prisoner might elect a bizarre or inappropriate form of execution. To frame the legislation, however, required to eliminate this possibility, would seem no great semantic challenge.

The second objection is much weightier in the context of my own ethical convictions—one of which is that capital punishment, *itself*, is a wrong. It allows no redress if a condemned prisoner is later proved innocent (an ethically, if not statistically, significant eventuality); and that it is not (vis-à-vis life-imprisonment) even a demonstrated deterrent to violent crime.

Those who hold that capital punishment is, itself, immoral, must then deal with the following difficulty: by allowing the condemned man this new possibility of achieving human dignity through his own execution, would we perhaps be rendering an evil recourse more palatable to the American people? Would this rightful dispensation to the condemned serve only to postpone by many years the eventual abolition of capital punishment?

Were it to do so, I would oppose the prisoner's request. But it is not certain that it would have this effect. It seems to me more calculated to remind the public that condemned men and women are not necessarily "mad dogs requiring destruction."

Since I view the condemned man, therefore, as still an end in himself, and not a mere societal means to the deterrence of crime; and since I do not think that accession to his request in this instance will necessarily enhance the acceptance of capital punishment (but might even lead to its further questioning), I believe the prisoner's request should be granted.

A Suicide Attempt & Emergency Room Ethics

After the car that he is driving at high speed hits a telephone pole, Mr. D is brought to the hospital emergency room in serious condition. The physicians who examine him recommend surgery to repair a major internal hemorrhage. But the sixty-eight-year-old man refuses, saying that he wants to be "left alone to die." The physicians also learn that three weeks earlier Mr. D was diagnosed as having carcinoma of the tongue. He has refused surgery for the lesion and has asked his own physician not to tell his wife that he has a fatal disease.

The hospital physicians believe that Mr. D will die without surgery for the hemorrhage, and they call a psychiatric resident to evaluate the patient. Dr. M interviews Mr. D and finds him coherent, rational, and alert. Mr. D describes himself as a man who values independence. He feels he has had a good professional life as an engineer, and a good personal life with his wife and two children. He expresses some sadness at his situation, but says, "I have had a good full life and now it's over."

Dr. M suggests, and Mr. D does not deny, that the automobile accident was a deliberate suicide attempt. What should Dr. M recommend? That the patient's treatment refusal for immediate surgery be accepted as the act of a rational person? That the refusal not be honored, and a court order sought on the grounds that a presumed suicide attempt is per se evidence of mental illness?

—Michael Jellinek

COMMENTARY

by RICHARD B. BRANDT

The prevailing law governing the requirement of consent for surgery was stated by Justice Cardozo in 1914: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault. . . . This is true except in cases of emergency, where the patient is unconscious. . . ." (*Schloendorff v. Society of New York Hospital*, 211 N.Y. 125, 129, 105 N.E. 92, 93)

There may, however, be exceptions if the patient's decision conflicts with overriding "state interests" in the preservation of life, the protection of the interests of innocent third parties, and the prevention of suicide. A refusal to accept treatment may not be suicide, since the patient himself does not set into operation a chain of causes leading to his death; but in this case the patient did (it appears) produce the injury for which surgery is contemplated. It is also unclear whether there could be a state interest in prolonging his life, in view of his disease, although another person's killing him would clearly be murder.

Further, some psychologists might claim that his sudden death in these circumstances could be psychologically damaging to his children, so there is a question about the impact on innocent third parties. Both the physician and court might wonder whether he had given careful thought to this potential damage. So it is not self-evident that a court would refuse to issue an order requiring the surgery. However, the specific question raised about this case is a limited one: whether the requirement of consent fails because the patient is not of sound mind.

In this case it would be sound legal practice, and seemingly morally unobjectionable and perhaps morally desirable, for the physician to seek a court order for surgery. The court order would provide a decision on some of these issues, and in any event it would clear the doctor and hospital of responsibility should questions arise later about failure to treat the patient.

Ought the physician/court to decide that a person's having made a suicide attempt is sufficient reason to judge him of unsound mind? Is a suicide attempt evidence of irrationality?

Let us consider some senses in which a person might show himself to be irrational:

1. If his objective is *manifestly* to *injure* himself, irrationality might be presumed (other things being equal, for example, if he is not attempting to help others by self-injury); but it is not manifestly a self-injury to attempt to shorten life in order to avoid the pain of death from tongue cancer. Evidently the present patient has decided that such action would not be self-injury.

2. A person is not rational if he fails to see the connection of means and ends, and refuses to take the means that are essential for his ends. The present patient is not in that condition; he sees precisely the consequences of his actions, and is acting so as to realize his end.

3. A person might be said to be irrational if his end is one he would not pursue if he knew, or anyway visualized clearly, what kind of thing his objective would be if realized. The patient appears not to be in this position. Tongue cancer is normally terminal, at least when not treated (it is so assumed in the description of the case), and a death from this cause is highly unpleasant to the patient and family.

4. A person might be said to be irrational if his end is one he would not pursue if he were not drunk, or seriously disoriented mentally, or in a highly emotional frame of mind. There is no evidence that the patient is in one of these conditions.

A judgment, then, that the patient is incompetent must rest on a conclusion about (1) that it is self-injury to shorten one's life in order to escape pain. It might be argued that the courts should try to prolong life no matter what. But courts have recently been more explicit in affirming what already seems to be public opinion: some treatment refusals are acceptable. (It is unlikely that any rational person would prefer to live fifteen minutes longer, in order to be burned to death, rather than shorten his life by taking a cyanide capsule, except on grounds of some moral conviction.)

Otherwise conservative philosophers

such as Philippa Foot hold that life is not worth living in a situation of extreme senility or of intense pain ("Euthanasia," 6 *Philosophy and Public Affairs*, 1977, 85-112). It is true that courts have generally tried to avoid qualitative judgments of this sort. In the present case, however, the patient himself has made a qualitative judgment after careful deliberation to the effect that the kind of life that lies ahead of him, if his life is prolonged, is not what he wants. If the court declares him incompetent, it is, in effect, substituting for his view its own about what kind of life is worth living.

The moral issue might be put in broader terms: would society be better off in the long run if physicians and courts did what is in their power to do, require people to undergo a painful termination of their lives when they do not wish to and when there is no evidence of irrationality beyond the very fact that they have made a decision not to live longer? It is not easy to see what would be the gain. On the contrary, there is the loss of needless suffering by the patient, not to mention his family; and the individual is deprived of assurance that he is in control of his own destiny in matters of most importance to him and which affect others only in an incidental way.

COMMENTARY

by ROBERT E. LITMAN

Dr. M, the psychiatric resident, should take action as follows:

1. He should notify Mrs. D, the patient's wife, and his children of the emergency. They should be interviewed by telephone and asked to come to the hospital;

2. Dr. M should get in touch with a senior staff psychiatrist, preferably the chief of the service, and request an immediate consultation;

3. Dr. M should initiate the legal process for a court order authorizing surgery.

If the patient demands his release from the hospital, the psychiatrist should be prepared to place him on a "hold" order for observation for mental disorder, because he is a danger to himself and to others. Another such suicide attempt might result in injury to a pedestrian.

Meanwhile, there should be a surgical consultation. If the surgeons find the patient's condition immediately life-threatening, then there is no time available for further persuasive efforts to obtain Mr. D's cooperation, nor sufficient time to obtain a court order. Given these emergency circumstances, the surgeons should proceed, trusting in the group consensus as a substitute for the consent of the patient, the family, and the court.

The hospital has an ethical and legal obligation to prevent further damage to Mr. D's life and health, and the patient has no ethical or moral right to demand that the emergency room doctors cooperate in his suicide efforts. By placing himself in the position of requiring emergency medical help to save his life, Mr. D has forfeited his autonomy for the time being. In the emergency room, the doctors are properly immersed in, and bound by, the ethic of saving lives; and these physicians, together with the other emergency personnel, simply do not have the time or the training to challenge this ethic in order to make exceptions for individual cases.

This is true in general for suicide attempters, and it is true in particular for Mr. D. The scant data we have strongly suggests that Mr. D's recent behavior has not been rational. I would not be inclined to accept his statement, "I have had a good full life and now it's over," as a rational self-evaluation in the given context; but instead, I would suspect that the statement probably represents a delusion of hopelessness, the direct result of depressive mental illness. It is quite likely that the physicians will learn from the patient's wife that there was a noticeable change in the patient's attitude several months ago, a change possibly connected with one of life's important transitions, for example, forced retirement from his job. And his refusal to allow treatment for carcinoma of the tongue because it is a "fatal disease" is another sign of his irrational hopelessness.

Clinical experience suggests that with appropriate psychiatric treatment, including a combination of antidepressive drugs and psychotherapy, the patient will feel much more hopeful in a month.

We can expect that within a month or two, this patient will have regained his full autonomy. At that point, if he chose to commit suicide, he might still do so, choosing, I hope, a method with less potential danger to other persons. Suicide is fairly common in the United States. In California, 2 percent of all deaths are by suicide. A person who is rational and relatively unambivalent about committing suicide can usually find a decisive and effective method for ending his life. Mr. D, on the other hand, chose a suicide method that is unusual, even bizarre, suggesting a great deal of ambivalence on his part. Given this degree of ambivalence, quite typical of suicidal persons, and the excellent treatment for depression that is now available, it is reasonable to expect that the hospital personnel take appropriate action to preserve Mr. D from further harm.

In principle, however, paternalistic action by physicians should be limited to emergencies, exceptional situations, and situations in which the use of authority is justified by the extreme difference in outcome that can be predicted from action versus inaction. For example, if a person has cut his or her wrists, and refuses remedial surgery, and the person's life is not in danger, I do not think that the surgeons are justified in immediately performing the reparative surgery on the grounds that a presumed suicide attempt is per se evidence of mental illness.

In summary, how Dr. M should proceed depends on how acute the emergency is, i.e., how many hours will elapse before the threat to the patient's life becomes irreversible. If Dr. M has time, he is urged to consult with the family and with other more senior psychiatrists and to use whatever time is available to persuade the patient to accept treatment, and failing this, to obtain court approval for emergency treatment. If there is no time, then doctors must proceed to remedial surgery with confidence in their own emergency room ethics. Although the patient's autonomy and self-determination is an important ethical value, Mr. D has sacrificed his autonomy temporarily by placing himself in life-jeopardy in the emergency room, an eventuality which could reasonably have been predicted when he drove his car into a pole. If it turns out that there is no treatable mental illness, he will, at a later date, regain his autonomy and his capability of disposing of his life as he chooses.

Practicing Procedures on Dying Children

Children's Hospital is associated with a major medical school and serves as one of several teaching hospitals for its pediatrics department. The hospital offers a complete range of therapeutic services; in addition, the staff carries out a wide variety of clinical and nonclinical research.

Because Children's is a teaching hospital, nearly all the patients are cared for by medical students, residents, and fellows. At every level of training the students are introduced to various therapeutic techniques by working directly on the patients—a practice that may be painful to the patient and unnerving to the students who must both concentrate on their tasks and try to soothe a frightened or crying child.

Among the many seriously ill children in the hospital there are usually several who are in a coma or who are near death. Since many of these patients feel little or no pain or discomfort, it has been proposed that the students initially practice on these patients. This proposal was supported by the claims that there would be less pain and trauma overall to the patients and the student's clumsiness and mistakes would have little significance for dying and comatose patients.

The patient-care committee is now examining the proposal. First, it must consider whether such a practice should be instituted, and second, if it is, whether parents of dying children need to be asked for consent. What should the committee recommend?

COMMENTARY

by EARL E. SHELP

The Children's Hospital described in this case is an institution with a threefold commitment. First, it is devoted to the health care needs of a specific population—children. Second, by virtue of its affiliation with a medical school, it embodies an investment in the education and training of medical personnel at every level. Third, it values the search for greater understanding as it encourages and participates in research activities. Ideally, both of these commitments to excellence complement and enrich the others. Realistically, however, they can conflict, loyalties can divide, and hard choices must be made.

The patient-care committee is asked to weigh the hospital's commitment to the care of patients against its interest in medical education. Specifically at issue is the treatment of a class of children who are near death or in a coma. The proposal to permit students to practice initially on these patients poses a primary question of justice and a secondary question of consent, or—more accurately—assent.

I assume that "near death" means that death is imminent and that pain associated with the disease is controlled by drugs. Further, I assume that "in coma" means that the child is insensitive to pain but that death may or may not be imminent. At issue is whether or not either condition is a sufficient reason to place on these children a burden not similarly borne by other patients.

The expected benefits of the proposed policy appear reasonable. However, these patients are not the only ones who can provide these benefits. Neither is the proposed policy risk-free. Other children receiving pain medication could share a similar insensitivity to a poorly executed procedure. Injuries that have long-term consequence could be sustained by nonterminal patients in coma. And, it could be argued that responsive, sensitive-to-pain patients would offer a better opportunity for the trainee to learn how to execute skillfully a procedure with minimal discomfort to the patient. Medical education requires that students learn from their patients as well as from their teachers. If this analysis is correct, then it appears that the proposed policy rests on a judgment that these patients are due less expert care because of a hopeless or guarded prognosis. Similar benefits could accrue by involving patients who are not facing imminent death or in a coma.

Interventions that have no power to cure are not morally required for the patient near death. Interventions that comfort are morally required, but this proposal jeopardizes that comfort. It implies that the intrinsic worth of these patients as persons has decreased while their instrumental worth as objects has increased. Whether or not patients in coma require therapeutic and/or palliative interventions depends, in part, on the assessment for potential recovery. Nonresponsiveness alone is not a sufficient reason to justify calloused care or a greater risk of injury. The moral tradition that urges the protection of the defenseless is long-standing. The powerful are obligated not to exploit the vulnerable. Parental assent to the proposed practice would not compromise the primary issue of justice.

It is a reasonable assumption that the parents of all children admitted to Children's Hospital are aware that it is a teaching institution, and that they accept, directly or indirectly, the fact that the major amount of routine care is performed by trainees at various levels under faculty supervision. The secondary question in this case is whether or not the parents of the described children, who are presumed incompetent to consent, should be asked in addition to assent to the proposed practices, if they are adopted. The request could be argued against on the bases of the implied assent at admission and the prospect for needless anxiety, suspicion, or distrust on the part of the parents. These are, at best, weak arguments.

If the proposed policy is adopted, even though it appears ill-advised on moral and pragmatic grounds, then parental permission would be preferable. Such a request would indicate respect for the dignity of the seriously ill child and the parental interest in the child's welfare. The character of the medical staff and the institution would be enhanced by this demonstrated sensitivity. One could reasonably expect an affirmative response to the request pro-

vided (1) that assurances of proper supervision could be given, and (2) that the child's increased risk of pain or injury is minimal. Gratitude or a desire to help others could motivate such a positive response from the parents, but a negative response should be respected.

But even with parental knowledge and agreement, the proposed policy is morally objectionable because it would impose an inappropriate burden on a particular class of patients not similarly borne by other patients. The duty of the staff and hospital to provide effective and compassionate care is not compromised by a dim prognosis. However, if the policy is adopted, parental assent should be obtained.

COMMENTARY

by NORMAN FOST

I take it to be self-evident that there can be no experienced physicians unless, at some point, procedures are done by inexperienced persons. The question, therefore, is not *whether* students should use patients for practice, but under what guidelines. I assume it is impractical for most of such training to be done with animals, models, etc., though these alternatives should be used as extensively as is practical.

At the point where a trainee must perform his or her first procedure on a patient, it should be done in a way that maximizes the benefit/risk ratio for the patient in the physical and psychological sense, as well as maximizing respect for him or her as a person. This can be aided in the following ways.

First, training should be restricted, as much as possible, to therapeutic situations. It is almost never necessary to use a patients solely as a means for "practice." It can and should be done at a time when a diagnostic or therapeutic procedure is indicated.

Second, the risks of discomfort can be reduced by doing such first attempts, whenever possible, on patients who feel no pain. It would therefore seem desirable, from the patient's perspective, to not only allow such training to occur when the patient is insensate, but to limit it as much as possible to such patients. I have in mind comatose patients who are expected to recover and who are therefore in need of therapeutic procedures. This would exclude most dying patients. Such a policy does not imply treating such patients with less respect than others, but in taking advantage of their insensitivity to pain, for the benefit of all patients, including themselves when awake.

Third, the risks of physical injury should be reduced by ensuring that trainees are properly instructed, supervised, and replaced when it appears the procedure cannot be competently performed. Training should obviously occur in stepwise fashion, starting with simple procedures and advancing as competence is achieved. Supervision would also increase the likelihood that the patient is treated with respect, and protect relatives from the psychological injury of seeing a loved one abused.

Fourth, risks could be further reduced by restricting training to those with a genuine need to develop skills. This would exclude most medical students, many of whom will go into fields requiring few or no procedural skills, or who will acquire them during residency training. Such training, therefore, should generally be restricted to residents and fellows.

Fifth, as with all intrusions, consent should be sought. The standards should be particularly high, since there would be, in part, a nontherapeutic component. If the patient were competent, such consent could be obtained at the time of admission (anticipating such reversible comatose states as post-operative recovery). In the majority of pediatric cases, proxy permission would be necessary. Parents should be suitable in most instances, though the community should be involved through advisory groups, public notice, and accreditation procedures. Consent could be included with the general admission procedures, though additional informing and discussion might be warranted in the ward setting.

There would be some procedures that could not be learned in a therapeutic setting, requiring the use of a patient solely as a means. I would not say it is always wrong to use a patient solely as a means. It would be wrong in the sense that it is a wrong-making characteristic of action, but all things considered, such acts would not always be wrong. This is only to acknowledge that ethical dilemmas always involve doing something wrong, in the sense that something of moral value is lost. I take this to be the essence of a moral dilemma.

The guidelines for permitting nontherapeutic intrusions on nonconsenting subjects for training purposes could be similar to those recommended by the National Commission for the Protection of Human Subjects regarding research on children. These would include: minimal risk; a substantial social benefit; no alternative way of achieving that benefit; proxy permission; and institutional review. In practice, this would permit nontherapeutic training activities such as physical examinations, and photographs, for example. It would not permit nontherapeutic interventions of more than minimal risk, such as cutdowns or lumbar punctures, on the grounds that there are less offensive ways of acquiring such training—namely, in the course of needed therapy on comatose patients.

These comments rest on the assumption that, as a practical matter, pediatricians-in-training must learn procedures on children, the majority of whom are incapable of giving consent whether comatose or awake. I would also assume that most children, if they had a moment of lucidity in which they could speak, would prefer that such practice be conducted during periods of unconsciousness.

Family Wishes and Patient Autonomy

Ralph Watkins, a seventy-five-year-old married man, was admitted to the intensive care unit of a university hospital in acute respiratory distress. He was anxious but fully alert and gasping for help. A retired laborer, Mr. Watkins had been suffering from a chronic pulmonary disease for the past fifteen years. For the past five years he had become progressively debilitated. Prior to admission he had been confined to his home and depended on his wife for the most basic of care: without her assistance he could not dress or feed himself. He had been a fiercely independent man and still enjoyed ordering people around. His wife and married son were totally devoted to him.

The diagnosis was bilateral pneumonia, and Mr. Watkins was given antibiotics and put on a mechanical respirator with supplemental oxygen. Within two weeks the pneumonia was largely cleared and Sarah Radburn, his physician, began attempts to wean him from the respirator. Unfortunately, he had become "respirator-dependent" as a result of a combination of poor nutrition, possible new damage to his lungs, weakened respiratory muscles, and fear of breathing on his own. Despite a slow, cautious approach with much reassurance, the weaning attempts repeatedly failed. Mr. Watkins, short of breath and terrified, would demand to be placed back on the respirator.

Dr. Radburn rated the ultimate chance for successful weaning as "maybe 20 percent." The patient became more and more discouraged with his lack of progress and the frequent painful medical procedures (constant intravenous feeding, frequent needle punctures for arterial blood gases, suctioning, and so on). After three weeks of unsuccessful efforts, Mr. Watkins refused to cooperate with further attempts at weaning. His wife and son became concerned that he had given up the "will to live." They begged the medical staff to "do something to save him." Although he had become less communicative, he remained alert and aware and, in the opinion of the staff, was fully competent. He told Dr. Radburn he wanted the respirator disconnected. "I want to die" he said.

What is the physician's responsibility in this case? Should the physician honor the patient's request? If we assume the patient is legally competent to make medical decisions, on what basis, if any, can the physician refuse or postpone acting on the request to stop life support? How much weight should be given the family's wish to "save" the patient?

COMMENTARY

by STUART J. YOUNGNER
and DAVID L. JACKSON

This case illustrates the often confusing and conflicting responsibilities that confront physicians in today's modern, high-technology medical environment. To preserve life, relieve suffering, do no harm, and respect the autonomy of this alert, competent man is no simple task. If Mr. Watkins were comatose or delirious, he could be declared incompetent and the family or a court-appointed guardian would make the decision. Confronted with the realities in this case, however, one could "solve" the problem most simply by taking one of two courses—both of which, we feel, are wrong.

First, one could insist that Dr. Radburn's primary responsibility is to try for the 20 percent chance of saving his life. After all, the patient placed himself in her care, and she can dismiss his wish "to die" as irrational, although not incompetent, and press on. This course is unacceptable because it violates the patient's autonomy. It also ignores the great degree of suffering and the small chance of regaining a "meaningful" life.

Equally simplistic, and in our view unacceptable, would be to respond to his expressed wish to die by immediately disconnecting the respirator, while piously proclaiming respect for patient autonomy.

It is noteworthy that both these courses (relentlessly pursuing treatment or rigidly following the patient's request) allow the physician to avoid a time-consuming and potentially painful dialogue with the patient and family. We suggest that before the respirator is disconnected and the irrevocable decision made to let the patient die, the physician must evaluate with the patient and family the following:

1. Does the wish "to die" represent a temporary depression in reaction to pain or a sleepless night? If the depressing situation passes or is adequately treated, the patient may well retract the wish to die. Of course, depression may be a realistic and consistent response to a situation of great suffering and little hope.

2. The patient's request may be a reaction of fear based on misperception or misinformation. Before stopping treatment the physician should identify any fears underlying a refusal of treatment and explore their source with the patient. Fear may be appropriate to many situations, and a reasonable basis for refusing treatment.

3. In similar intensive care units, we have seen several cases in which patients have exhibited true ambivalence about stopping treatment. If adequate dialogue is not established, the physician may hear only that side of the ambivalence with which he or she agrees. Acting on such half-truths is hardly honoring the principle of patient autonomy.

4. A patient's request to have treatment stopped may be a symbolic attempt to regain control in a situation in which he has none. A critically ill, machine-dependent patient has little autonomy in the most mundane and basic aspects of his life such as sleeping, elimination, eating, and privacy. He is totally at the mercy of others. The request for termination of treatment may be a desperate effort by a helpless patient to get the attention of his family and caregivers and to assert his independence. Thoughtful investigation may discover alternative measures that restore the patient's sense of autonomy and with it a revival of the wish to pursue life vigorously.

5. An apparent clash between the

wishes of the family and patient may identify underlying problems of communication between them. The physician must clarify with the family the meaning of their cry "to save" the patient. Are they acting out of guilt? Can they distinguish their own needs from those of the patient? A meeting with patient and family together may be the only means of clarifying the apparent disagreement. If the issue cannot be resolved the patient must have the ultimate input to the decision-making process. The physician's contract is with him and ultimately it is his fate being decided.

The possible interventions and evaluations we have suggested will postpone acting on a patient's request to stop treatment. In doing so we could be accused of "paternalism" and violating the patient's autonomy. However, as Eric Cassell (*Hastings Center Report*, December 1977, pp. 16–19) has pointed out, a sick person is not simply a well person with an illness appended. Life-threatening illness, dependence on machines, and the ensuing physical and psychological regression make the concept of autonomy much more difficult to apply. By postponing an irreversible decision until important issues can be clarified, physicians may not be violating the true autonomy of their patients. Reflex acquiescence to patients' wishes that treatment be stopped may be a way for physicians to avoid close dialogue with fellow beings in their hour of greatest need. If the dialogue is completed and the patient's wish to die remains, there is almost always time to withdraw life supports.

COMMENTARY

by WILLIAM RUDDICK

In order to sharpen a single issue I shall assume that the courts, the hospital's regulations, and the physicians' professional and moral principles do allow patients in such circumstances to refuse life-saving treatment. Nevertheless in this case as sketched, Dr. Radburn should first explore the conflicting requests. Her first responsibility is to make sure that the patient's request expresses an informed, autonomous, and resolute desire to die and is not merely a show of "fierce independence."

Suppose that various inquiries convince the physician, staff, and consultants that the patient means what he says for reasons appropriate to his age, condition, character, and other circumstances. His pain is tolerable, but his increasing and irreversible debilitation and dependence are not. Even ordering people around has ceased to relieve his "burdensome" life. Despite his family's pleas, he wants to die—even if he can still be weaned from the respirator.

His wife and son want him kept alive, even if he cannot be weaned. They realize they have no legal means to prevent the physician's termination of treatment, but if the physician refuses the patient's request, they trust that he will be too weak to enlist legal aid (or to turn off his own respirator). For reasons of affection, shame, and "philosophy of life and death," they prefer his forced survival to his death by what they perceive as suicide.

These elaborations simplify the case:

1. The probability of weaning becomes irrelevant: the patient wants to die, even if weaned; his family wants him kept alive, even if respirator-dependent;

2. The direct conflict of their desires shows that the patient is not influenced by self-serving family suggestion or fear that he has become a resented burden;

3. Free of all other opposition to terminating treatment, the physician must base any refusal or further delay solely on the family's desire.

What then are the physician's professional and more general moral responsibilities? Should the family's desire, or considerations of their welfare, deter her from "honoring the patient's request"? I think not. The family is not her patient, nor the patient's proxies. Nor does his decision or welfare depend on their own. A physician often has a derivative responsibility for the welfare of family members who can provide a patient with hope, courage, nursing or financial aid, or legally required representation. But she has no such derivative professional responsibility for the family's welfare here. Indeed, to the extent that she shares her patient's belief that he would be "better off dead" or would die better now than later, she must oppose those who would forcibly continue treatment. A family's welfare does not compete with, let alone overrule, a patient's welfare in a physician's deliberations.

Though not professionally responsible *for* the family, Dr. Radburn is nonetheless responsible *to* them in at least two ways. Given their concern and past care for the patient, they are owed a thoughtful account of the decision to terminate treatment. Whether or not they are employing her, the physician must answer to them for the proposed course of action. Moreover, benevolence requires her to try to reconcile the family to her decision. If their religious principles cannot be interpreted to permit termination, she may only be able to prepare them for the patient's death. Even if the patient is being selfish in his distress, the physician should take concern for those he is (excusably?) ignoring and harming. And even if he is acting "within his rights," benevolence requires the physician to moderate the avoidable suffering produced. The demands of virtue cannot block the exercise of rights (otherwise rights would lose their force), but they can delimit the manner in which others facilitate the exercise of those rights.

In summary, the physician has two grounds for delaying, but none (as the case is elaborated) for denying the patient's request. Time is needed for: (1) making sure that the patient's request expresses a deliberate, resolute desire; and (2) trying to lessen the suffering of the family whose plea she professionally should reject but morally must respond to with compassionate attention. The first delay involves a paternalistic defense of a patient against undue influence by haste, pain, drugs, or others whose desires and welfare are not an integral part of the patient's own concerns. (This "subject paternalism" appeals to a patient's *characteristic* desires, not to his or her "best interests.") The second delay is justified by the coordination of rights with virtues that limit the manner of their exercise, especially with regard to the cooperation of the physician and the suffering of the family. Like any right to life, any right to die must be located in a context of virtues, as well as of other rights. Contrary to current slogans, people do not die alone.

5

Human Subjects Research

Parental Consent and a Teenage Sex Survey

A research team has designed a project; one essential element is a prospective study of adolescent sexuality. The study will gather information about the transition from sexual innocence to experience among teenagers by surveying sixteen and seventeen-year-olds. According to other research, a large number of young people of this age are sexually inexperienced or somewhat experienced. The data collected will be recorded by an identification system that will maintain the subject's privacy. The information from the survey is expected to give doctors, teachers, parents, and counselors a better understanding of adolescent sexuality and to provide a sound basis for designing sex education programs and clinical services for teenagers.

The research team is faced with a serious dilemma in seeking consent. While they plan to seek consent from the young people being surveyed, they cannot decide whether to seek parental consent as well. Previous attempts to conduct such surveys have foundered on this issue. One study in which a great many parents of a randomly chosen pool of teenagers failed to give consent was criticized for being unrepresentative. Furthermore, since adolescents do not need parental permission for sex-related medical care, why should it be sought for a survey? On the other hand, this is a sensitive issue between parents and their adolescent children as well as in the communities where the surveys will be done. What should the research team decide?

—E. James Lieberman

COMMENTARY

by DONALD RICHARD NILSON

The research team has decided to seek the consent of participants in this well-designed prospective study because they will record and maintain information by personal identifiers until the data-collection phase of this project ends. Consent is necessary to protect the subjects from harm that might arise through the unauthorized distribution and use of these self-reports.

The teenagers who have personally consented to be subjects in this survey (and others) should be allowed to participate without interference, in particular, *without* the consent of their parents or legal guardians. Support for this judgment arises from at least two sources: one *social* in

character—the free acquisition of information pertaining to social issues; the other essentially *individual-centered*—the research subjects' rights to self-determination, privacy, and free expression.

Intelligent social action presupposes positive knowledge about society and the role of the individual. Seriously facing and realistically attempting to solve societal problems requires that carefully acquired, reliable information concerning the causes and conditions surrounding these problems be available to policy- and law-makers, educators, counselors, and so on. Wherever possible, the social scientist (acting on behalf of society) must be free to conduct research without interference, except where supervening or overriding interests are at stake. Any measures which interfere with the process of acquiring data, or for that matter other phases of such experiments, are *prima facie* unacceptable and should be resisted by the scientist, if necessary, through social-legal action, unless the measures can be shown to be necessary for the protection of the subject.

Recent studies of adolescent sexual experiences have shown excellent response rates and no evident adverse effects when minors were allowed to participate without parental consent (J. F. Kantner and M. Zelnik, "Contraception and Pregnancy: Experience of Young Unmarried Women in the United States," *Family Planning Perspectives* 5: 21-35, 1973). When parental consent is sought, response rates fall to an unacceptable level (R. C. Sorensen, *Adolescent Sexuality in Contemporary America,* New York: World Publishing, 1973).

Minimal changes in behavior (about 2 percent of participants report direct effects) can be attributed to participation in surveys on human sexuality, and the benefits resulting from greater reflection and increased knowledge clearly outweigh any potential damages (B. N. Fujita, et al., "The Effects of an Interview on Attitudes and Behavior," *Journal of Sex Research* 7:138-152, 1971). The collective significance of these empirical studies is that potential negative effects on subjects arising from their participation in the type of study described in the case are minimal and clearly are insufficient to justify requiring parental or guardian consent.

The argument for this same conclusion based upon individual rights is even more straightforward. Individuals much younger than the potential subjects of the adolescent sexuality survey are entitled to the free expression of their opinions and a full measure of privacy, morally and constitutionally. While the topic of the rights of children involves many troubling, unresolved, and fundamental issues, clearly minimal rights of children include their own personal control of information about their lives, beliefs, and actions. Of course, the rights and privacy of parents and guardians must also be protected, but these should be protected through confidential handling of survey results and legal sanctions.

The research team is responsible for assuring the subjects that the data they provide will be handled with discretion, but at present there are limits to which this assurance can be made. If data are released by the research team and can be traced to individual respondents, current legislation and regulations suggest that the research team is liable to law suits by the respondents and will suffer damages. If data are demanded by the state through writs of subpoena and not released by the research team, again they can be penalized. If physicians can enjoy testimonial privileges with their patients, and lawyers with their clients, then we believe that researchers should enjoy testimonial privileges with their subjects. This dilemma of limited assurance needs to be resolved, but sufficient reasons now exist for the research team to handle these data very cautiously.

Centering the discussion in this case study upon surveys of sexual behavior is necessary, but it is fundamentally misguided to tie the issue of informed consent exclusively to research pertaining to sexual behavior, and genital sexuality in particular. We regard sexual behavior as continuous with general and total self-expression. Thus, interpersonal behavior and a wide range of forms of expression are as much in need of social scientific study *and* adequate protection of the subject-participant as is the narrower, but presently more socially sensitive, range of behavior treated in this case study.

COMMENTARY

by MARGARET O'BRIEN STEINFELS

Federal regulations designed to protect research subjects have been vigorously criticized by social science and behavioral researchers. They argue that the kind of research they do entails minimal or no risk and, therefore, does not require the degree of subject protection which biomedical research may require and for which the federal regulations were intended.

In the light of these regulations, the researchers conducting this survey of adolescent sexuality might argue that since they are not exposing a minor to risk, that is, "to the possibility of injury, including physical, psychological, or social injury," they are not required to seek parental consent. They might further argue that young people, certainly sixteen- and seventeen-year-olds, are developmentally capable of giving consent, a point supported by their reference to the adolescent's right to obtain sex-related medical care without parental consent. (Note, though, that the Supreme Court struck down parental consent requirements in this area on privacy grounds without ruling on the adolescent's capacity to consent).

Seeking therapy is a significantly different act from participation in non-therapeutic research; equating the two because they are both sex-related ought not obscure the relatively different balance between risk and benefit in each case. And precisely in examining the possible risks in the research survey does it become clear that most adolescents do not have the experience or critical faculty to adequately judge risk to themselves. Therefore their parents' consent as well as their own should be sought.

Two arguments can be made in favor of requiring parental consent for all research on minors. First, most parents are better able to calculate the actual risk to an individual child and protect him or her from it than a researcher who can only predict probable risk to a group. Indeed, a statistically minor risk for a group, like 1 or 2 percent, could mask a significant risk for an individual in that minority. Second, the regulation requiring parental consent for research on children recognizes, as a matter of public policy, that parents ought to be the final judge in matters concerning their minor children.

Although parents may not know the exact state of their child's knowledge or experience, particularly in sexual matters, they are likely to know their child's vulnerabilities; they can find out how intelligently and carefully the researcher or interviewer will respond to any question or concern their child may raise during the survey. They can also ascertain whether the child understands the nature of the survey and the kinds of questions that will be asked before the child gives his or her own consent.

Depending on the setting, parents may be concerned about the degree of privacy and confidentiality their child will enjoy. If the survey is conducted in a school setting, will school personnel have access to the responses? Will the fact that any particular child has participated in the research be a matter of public knowledge even though individual responses will be kept in confidence? After the data are analyzed, will the researcher sufficiently disguise the settings and individuals so that publication will not breach the confidentiality or anonymity of the subject?

Other more general risks may concern a parent but may be ignored, minimized, or denied as being relevant issues by the researcher.

Most researchers regard data-gathering as a value-free activity; they are seeking information or opinion in as neutral a manner or formulation as possible. But the mere act of asking a question suggests interest, not neutrality. "How many times have you had sexual intercourse in the last week? month? year? How many times have you had sexual intercourse with a person of the opposite sex? same sex?" Such questions to an adolescent are about as neutral as the classic "When did you stop beating your wife?" They imply an attitude and an opinion, which may leave even the most sophisticated adolescents in a quandary about what his or her values and practices ought to be. Information flows both ways in survey research and precisely because the message that comes from the researcher is ambiguous and subtle, parental concern is justified.

Matters of sex (as of other serious matters like violence, politics, drug use, work habits, racial attitudes, and religion) are likely to be subjects about which most parents do not feel neutral, and they do not want their children to be neutral either. Will the family's own values be subtly undermined by the "value-free" formulations of the questions and the authority under which the questions are asked, including, by virtue of their consent, parental authority?

Under whose auspices and for what purpose is the research survey being conducted? There are differences between Planned Parenthood, Right-to-Life, *Hustler* magazine, Parke-Davis, Columbia records, and the manufacturer of Trojans—all organizations potentially interested in adolescent sexuality. Parents might reasonably see greater risk in sponsorship by some rather than others. Or, in a survey of racial attitudes, parents might want to distinguish between research sponsored by HEW, *Time* magazine, the NAACP, and the United Arab League.

And what of the purpose of the research? We are told that this survey of adolescent sexuality will lead to improved sex education programs and clinical services for teenagers. Should parents refuse to consent, if they see these purposes, or those of any research project, placing their family values at risk? Although, "a fair explanation of the procedures . . . and their purposes" is the first requirement of informed consent in the HEW regulations, researchers may argue that the *purpose* of the research should not be subject to scrutiny under consent procedures and that to refuse consent on these grounds unreasonably hinders their efforts.

But let us shift the issue to areas other than adolescent sexuality. Black parents might reasonably refuse consent for a survey conducted by Arthur Jensen, or those who hold his views, on the grounds that the outcome of the research undermines their efforts to secure equal education opportunities for their children.

Parents of developmentally impaired children may be reluctant to consent to a survey whose purpose is to develop a tracked system in local schools.

If parents see risk where researchers see none, these examples suggest why. What the researcher regards as disinterested information gathering may be seen by parents as jeopardizing their ability to protect their child from harm and as undermining the family's moral, political, or social values. What is a factual issue to the researcher may be a moral one for the family.

Given the value-free and scientific premises proclaimed by most research, it is impossible for researchers to acknowledge the fact-value paradox in the way they work. The best protection then for children and family autonomy in child-rearing is to maintain the parental consent requirement for research with minors.

Studying Grief Without Consent

John Clark, a graduate student at a major university, wanted to research the emotional needs of families who had a dying relative. He decided that the best way to conduct this research was to work as a participant-observer in a hospital. He already had training and experience as a counselor, and he added to his qualifications by taking a course to become a nursing assistant.

A small community hospital interested in family care allowed him to volunteer for ten hours a week as a nursing assistant and counselor. The hospital had never conducted medical research before, and had no committee for the protection of human subjects. In fact, none was required by state or federal law at the time. Clark informed the administration and staff of his research intentions and received their approval for his work.

Working in the intensive care unit and the emergency room, Clark gave basic care, took vital signs, and assisted the nurses. When a critical care patient was admitted to the unit, he was assigned to work with the family. He provided counseling, helped them deal with the hospital administration, acted as an information liaison between staff and family during nonvisiting hours, and stayed with the family when they were told of the death.

Following each death, he wrote a case history and maintained a check list of common grief reactions. He showed these reports to no one. After a period of three months, he wrote a paper reporting his findings. From this study, the staff developed a course to teach nurses how to deal with the critical care patient's family.

The families Clark counseled were told only that he was a nursing assistant and counselor working with the hospital to give special attention to their needs. They responded very positively to the services that he provided. They were not told that a research project was being conducted or that a study would be written.

Clark later decided to use his study as a central part of his doctoral dissertation, and to extend his research where necessary. The university at which he was enrolled had an active research review committee for the protection of human subjects, which was required to examine all research conducted under its auspices.

Should Clark and the hospital have obtained the consent of the families to participate in the research even though it was not legally required? Should the chairman of Clark's department now send the research study to the university's review committee? If so, what should the committee recommend?

—Linda M. Colvin-Rhodes

COMMENTARY

by MICHAEL JELLINEK

I find it difficult to apply the current sophisticated and sensitive guidelines on human experimentation to studies done years ago, in small hospitals, reviewed by administration and staff, and integrated into a program of therapeutic and humane care; therefore I do not believe it was necessary for Clark to obtain the consent of the families he studied. However, present standards clearly define Clark's work as research. He is planning, prospectively, to collect data using systematic methodology as part of a doctoral thesis. If further research is planned that includes patients of their family as subjects, then the departmental chairman has an obligation to send the proposal to the university research ethics committee.

Within a traditional view of medical ethics, Clark by definition is not exclusively oriented to the clinical needs of his subjects. The nature of the clinical interview and Clark's empathetic response may be significantly influenced by the demands of his research design. Further, the patient must give the physician permission to discuss the nature of the illness with the family. Only in unusual circumstances dictated by clinical necessity or urgency should the physician disclose information to the family without the patient's consent. Beyond consent requirements, the university committee will have to review the study's methodology to determine if the risk to the family members' psychological well-being (for example, a structured interview meant to test the subject's defenses) is worth the potential gain in knowledge about the grieving process. Mr. Clark will be discussing very sensitive material with his subjects and therefore the committee will have to be sure that their confidentiality will be protected.

Within a contractual perspective, Clark has an obligation to respect the autonomous functioning of the patient and the family. The committee must assure that both have the opportunity to exercise free will. Without consent patients and subjects may well wonder why they are receiving special attention or additional services. If they discovered a covert research project was the basis for these additional services rather than Clark's or the hospital's therapeutic concerns, they may well feel angry, hurt, and devalued. I would also ask the committee to consider whether the therapeutic counselling service should not be offered even if a research subject declines to participate.

If Clark's goal was to report retrospectively some of his experiences, assuring confidentiality, and in an experiential rather than systematic manner, then conceptually his work could not be distinguished from those physicians whose recognition of patterns of disease has served as the basis for modern clinical care and research. It is virtually impossible to burden physicians who retrospectively organize clinical impressions with consent requirements. If Clark reviewed computerized hospital records and maintained confidentiality, then again consent would not be necessary. Further I do not want to stifle physicians' curiosity and creativity within the context of optimum patient care, and therefore have them ponder

every new question or marginal laboratory test to see if it conforms rigidly to common practice and, if not, requires research level consent.

The only certain assurance that research will not result in a loss of trust between physician and patient is the integrity of the investigator. I would ask the committee to review Clark's past work and the departmental chairman's recommendation. Given the area of research, the committee's risk/benefit review of the proposal, and the likelihood that Clark is sincere, I believe that a brief oral consent from both patients and subjects would be appropriate to the clinical setting of the seriously ill individual and anxious family. Clark should submit a written form of a proposed oral consent, and should use the approved consent early in the interview.

COMMENTARY

by RUTH MACKLIN

Few moral rules are without exceptions. The widely accepted principle requiring those engaged in research or therapy to gain informed consent from subjects or patients rests on fundamental ethical precepts: respect for the privacy of individuals; protection of confidentiality in settings where privileged information may be divulged; and preventing harm from befalling innocent persons.

Does this case violate the moral imperative that people should be treated as ends in themselves, never solely as means? I shall argue that it does not. Should Clark and the hospital have obtained consent from the families even though it was not legally required? No, provided that all appropriate steps were taken to protect the identity of those whose case histories were written up and whose grief reactions were recorded.

As unpopular at this conclusion may seem to those who zealously defend the need to gain informed consent for every activity that might properly be termed "research," I think both common-sense morality and leading principles of ethics can support such a conclusion.

First, consider what the families whom Clark studied were told. It is true that he was a qualified nursing assistant. It is also true that he was a trained counselor working with the hospital to give special attention to the families' needs. What they were *not* told is that in the course of providing his services, Clark was writing up their case histories as part of a research study.

Does this act of withholding information amount to a form of deception? Arguments could be offered in support of either a "yes" or a "no" answer. It is surely true that an important piece of information about the nature of Clark's overall activity was intentionally omitted. On this count, it could be argued that the activity was deceptive. On the other hand, nothing in the description of Clark's behavior suggests that he intended to mislead these families in some way crucial for getting significant results. Unlike the myriad examples of social science research in which subjects are deliberately lied to or manipulated in ways the researcher deems necessary for obtaining his results, this case embodies the blandest form of deception —if it can properly be described as deception at all.

But let us grant, for the sake of argument, that an element of deception *is* present when a portion of the facts is withheld. Does this automatically make an activity morally wrong? Only the most rigid adherents of the rule "Don't deceive" would say "yes" to this general question. Clearly, these families were not being treated *solely* as means to another's end. Clark counseled them, helped them deal with the hospital administration, stayed with the family when they were told of the death—all actions that signify treating persons with dignity and respect.

Suppose Clark *had* sought to gain consent for his study from these grief-stricken family members. Is it likely that consent would be both fully voluntary and rationally informed? Probably not, given our knowledge of human behavior in time of grief. Some families might have granted consent but it is questionable whether any consent gained under such trying circumstances could meet the test of being freely and rationally given. Some families might have refused consent, possibly lessening their chances of receiving the services Clark was so ably providing.

Clark's failure to obtain consent from these families would amount to a violation of moral principle only if the identity of the individuals were not kept confidential. Recording common grief reactions and reporting anonymous case histories is no more a violation of moral precepts, when confidentiality is preserved, than writing a piece of fiction based on real-life incidents where the names and places are changed to protect the innocent. The families were helped—not harmed—by Clark's services. It appears incidental, from a moral perspective, that he was conducting a study in the course of his counseling and other helping activities. Had he manipulated these families, or treated some differently from others in order to observe varying responses to his own actions, it would have been a different story—an experiment in social psychology requiring consent of the subjects. But none of these families was used as an "experimental control." Current concerns over the protection of human subjects of research may have swung the pendulum too far in inducing the belief that every activity labeled "research" morally requires the consent of those studied.

These conclusions notwithstanding, the chairman of Clark's department should send the research study to the university's review committee. This would not only be expedient, but also an honest way to proceed. The committee in turn should recommend that the previous studies be accepted. Finally, the extension of Clark's research should be approved so long as it succeeds in meeting the morally necessary conditions: that the identity of the subjects be kept strictly confidential; that no manipulation or deliberate lying take place; and that these suffering families continue to be treated as ends in themselves, never solely as means to a researcher's ends.

Can a Research Subject Be Too Eager to Consent?

Lila Goldberg, age twenty-one, was admitted as a voluntary patient to the adult psychiatric service of a large university teaching hospital because she had lost thirty pounds in six months and extensive out-patient medical evaluation had failed to reveal an organic basis for the weight loss. After the diagnosis of anorexia nervosa was confirmed, the patient was placed on a high-calorie diet and a behavior modification program supplemented by individual psychotherapy.

One week after admission, Steven O'Connor, a psychiatrist affiliated with another ward, solicited Ms. Goldberg's participation in a research project that would measure the concentration of biogenic amines in the blood and spinal fluid of patients suffering from anorexia nervosa. This investigation was not intended to be of direct clinical benefit to the patient. However, the study could conceivably provide information about the presence of any underlying neurophysiological abnormalities in this disorder. Ms. Goldberg readily agreed to be a subject and signed a thorough informed consent form for the protocol, which already had institutional review board (IRB) approval. As a participant she would have blood drawn by vein several times and would undergo three lumbar (spinal) punctures—procedures that carry a high risk of discomfort and a low risk of infection.

Lila's psychiatric nurse, Sharon Miller, questioned her patient's inclusion in this study. Having observed that all anorectic patients eagerly agree to participate in studies despite discomfort and potential harm, Nurse Miller reasoned that psychiatric illness made an anorectic patient overly cooperative and thereby masochistic. The patient's willing participation in the protocol could be construed as another anorectic symptom. Dr. O'Connor countered that Ms. Goldberg was fully competent to volunteer. Should she be allowed into the study?

COMMENTARY

by SPENCER ETH and CHERYL ETH

Lila Goldberg, described as an adult who is not retarded, psychotic, or mentally incompetent, has voluntarily entered a hospital for treatment of her mental illness. There is apparently no hesitation accepting her consent for hospitalization, diagnostic procedures, and treatment. Unexpectedly, however, objections are raised to her participation in a research protocol. The argument is based on the peculiar nature of her illness—that anorexia nervosa causes a specific impairment of critical judgment, which greatly increases the likelihood of a variety of self-destructive behaviors.

Anorexia nervosa is a mental illness that primarily afflicts adolescent girls. Typically, those affected retain their intellectual abilities and can often continue to function until the illness has progressed to the point of serious medical complications. In fact, the contrast between an emaciated appearance and persistent dieting and hyperactivity may be the only clue to this potentially fatal illness.

A prominent personality feature of anorectic women is submissiveness. Many are described as "perfect children." The manifest need to be cooperative, even obedient, propels anorectics into perpetual self-sacrifice. Often the patient's life before the onset of anorexia has been a series of attempts to live up to the expectations of family and friends, along with fears that she will fail to be the "best little girl." Starvation may be the sole area in which she expresses her independence and mastery. The patient is locked into a behavior pattern (starvation) much as the alcoholic is compelled to abuse liquor despite the dreadful consequences.

In situations where the anorectic must satisfy her unconscious need for self-punishment, her capacity to act as a moral agent is diminished. Offering the anorectic an opportunity to participate in an experiment associated with discomfort is comparable to offering a heroin addict the chance to be in a morphine metabolism study. Two dangers of research are (1) probable risks or injuries to subjects that exceed anticipated benefits; (2) the possibility of injury to the person's autonomy and moral integrity. Dr. O'Connor's study clearly carries no substantive physical risk. But without additional protection anorectic patients are vulnerable to moral injury whenever they are solicited for research.

An additional safeguard is needed to supplement rather than replace the anorectic patient's own informed consent. This mechanism might operate as follows: if the anorectic declines to enter the study, her decision alone suffices. If she wishes to participate, then a concurring opinion is required prior to her acceptance.

But who shall serve in this role of patient advocate/guardian? We would eliminate some obvious choices. Local IRBs should not become involved in the mechanics of securing consent. The psychiatrist, whose duty is to provide treatment to Lila Goldberg, faces a double-agent problem of divided loyalties if he is also acting in his colleague's behalf. The patient's parents, if they are available, are usually concerned, but the psychological conflicts at work in anorexia deeply enmesh the family in the patient's illness. One alternative would be a patient representative or subject advocate appointed by the state or by the hospital. However, a much simpler solution is to turn to the professional psychiatric nurse. She possesses the minimum of a bachelor's degree in nursing and two years of psychiatric nursing experience, which should ensure knowledge of the research process, proficiency in interviewing, and the ability to assess the patient's capacity to function in the psychological, social, behavioral, and medical spheres.

The designated nurse should have no vested interest in the research project nor should she provide primary care to the patient. She could be a consultant who would interview the patient until key data were collected. If the patient wished to enter the study and the nurse determined that participation was self-destructive, the patient would be excluded. This independent veto

power is analogous to the nurse's role in disapproving a psychiatric patient's pass to leave the hospital if the pass request is deemed clinically inappropriate.

This consent process does not guarantee a wise decision, but it does minimize the risk of collusion with an anorectic's self-destructive impulse. There are drawbacks—added expense and inconvenience, diminution of independent decision making, and the creation of an impediment to research—but the important advantage is that it protects the moral integrity of the patient.

COMMENTARY

by HAROLD EDGAR

In all likelihood, Ms. Goldberg should be allowed to participate in the research. Before so voting, I want to discuss the matter briefly with my IRB.

First, Ms. Goldberg has been admitted to the hospital for treatment. Presumably Dr. O'Connor, from a different ward, has consulted her physician to assure that this physician knows no reason—physical or psychological—why Ms. G should not consent. If not, Dr. O' acts wrongly. Does the IRB have a rule covering this situation? Is one needed? Is there any doubt about the impropriety of administering unnecessary spinal taps to patients for whom one is not responsible and about whom one knows almost nothing?

Second, commentators too often ignore nurses and other hospital personnel in discussions of medical ethics. They see patients more often, and in more varied circumstances, than physicians usually do. Nurse Miller, a psychiatric nurse, may be especially capable of discerning a particular patient's inability to understand and act with conventional rationality about a research protocol. Such a patient should not be asked to risk serious pain and discomfort in research not directly benefiting her. I believe lumbar punctures pose such a risk. Am I wrong?

Nurse M's objections, however, are not based on observations of Ms. G. She has developed her own theory of anorexia: *all* anorectics are willing to suffer in others' behalf, and this trait is part of their disease. She reasons further that consent produced by "disease" is not free and meaningful.

Her evidence is scant. From what we are told, it is simply that everyone says "yes" to Dr. O'. Are not other explanations of the patients' behavior much more likely? Is Dr. O' informing patients of the possible discomforts in a fair way? Researchers want potential subjects to say "yes" when asked to join an experiment. Researcher enthusiasm may be desirable, and is inevitable anyway. The policy problem is to temper enthusiasm in order to minimize unnecessary risk-taking and to assure subjects a fair choice.

This responsibility now falls partly on IRBs. Few IRBs check systematically whether the research they approve is in fact understood by the patients who sign up. Should they? Broad questions about IRBs and whether there may be better ways of accomplishing their mission are beyond the scope of this commentary. As a practical matter, however, making sure that researchers do not inappropriately encourage volunteering is complex for reasons other than the difficulties inherent in policing a hospital. Briefly, a physician's confidence may be helpful to patients in many settings. Requiring a skeptical presentation can compromise a physician-patient relationship. Moreover, what is a physician to say when the patient asks for an opinion on whether to volunteer? These are problems of research on nonvalidated therapies however. In experiments such as this one patients should be told bluntly that there is no chance, or no reasonable likelihood, that undergoing the procedure will help them. Researchers sometimes shy away from such candor. Consent forms often include boilerplate statements such as "we hope this research may be of benefit to you" in circumstances where there is no such chance. More important, researchers may wrongly convey such impressions in seeking consent.

All the patients Dr. O' has approached have volunteered. Should this trigger another look at the protocol? Most IRBs do not keep track of such percentages with a view to rechecking the consent process if the level of volunteering seems out of line with our intuitions about readiness to take risks. We should be cautious, however, in assuming that everyone is against risk taking. Persons suffering from a baffling and life-threatening problem might well risk discomfort to help others similarly afflicted. Anorectic patients may have a special desire to learn that their problems have a direct biochemical cause.

The case assures us that the consent procedure is full and fair. Thus, it remains only to discuss with the IRB Nurse M's observation. Is it true in the experience of the medical members that anorectics uniformly sign up for research regardless of what it entails? The researchers I have questioned casually say that anorectics are pretty much like everyone else. Some say "yes" and some say "no" to research participation. If that is the case, there is no reason not to proceed with the research.

We presume adults' statements are legitimate signs of their preferences over a vast domain of activity, and we respect such preferences although we realize that people may not truly know what they want. Similarly, we act on the words they say recognizing that people often do not say what they mean or mean what they say.

To be sure, no rule is absolute. We disallow some preferences, and we correct for mistake and fraud in many contexts. But, there is no fraud or mistake here. Moreover, Ms. G does not fit a narrow category of persons whose ability to process information and relate it to themselves is so sharply limited that to credit their "statements" would undercut respect for the principle of autonomous choice. No claim is plausible that Ms. G's agreement is uniquely determined by a condition foreign to her character.

The mentally distressed have as vital a stake as the rest of us, if not more so, in assuring the conservative administration of doctrines that deny significance to individuals' statements of what they want. Surely we are not going to monitor all Ms. G's choices, and disregard whichever ones we think occasion more suffering than likely benefit. To assume that her choices in this context require a unique capacity beyond that required for everyday affairs is to elevate medicine and research to an undeserved status. To make informed consent the tool for finding such a capacity will convert it into an elaborate fiction.

The Last Patient in a Drug Trial

A thirty-year-old man was admitted to the hospital for chemotherapy. Eighteen months earlier he had had an above-the-knee amputation for a malignant tumor of the right foot and was considered free of disease. A month before admission a chest x-ray showed multiple areas of metastatic tumor throughout both lungs. For several weeks he was treated with a combination of conventional chemotherapeutic drugs that are sometimes effective against this type of tumor. This patient had no response, however.

Normally, he would now be a candidate for treatment with an experimental drug. In this instance, the drug currently being tested has shown no antitumor effect in any of the eighteen patients with this form of cancer who have received it. Toxicity has been typical for an experimental anticancer agent. All the eighteen patients experienced significant nausea and vomiting for about forty-eight hours after taking the drug. Several patients developed sores and ulcerations in the mouth for several days, and almost all had temporary severe decreases in their blood counts. Two patients developed pneumonia as a result, and were treated with antibiotics.

If no responses were seen, the trial of this drug was originally designed to end for this type of cancer after nineteen patients. The physicians in charge of the trial could then say with 95 percent confidence that the drug would be effective in less than 15 percent of patients with this kind of tumor, and thus that this drug had little usefulness against this form of cancer. This patient is the "last" patient in the trial—unless he responds, the trial will be closed. The patient wants to be treated. The physicians in charge of the trial are anxious to finish the study so a definitive judgment can be made on the usefulness of the drug.

Is the physician obligated to treat the patient with another drug that "might" work rather than to complete the trial? Does the fact that the research team "knows" the drug is ineffective affect the patient's informed consent? Do the physician's obligations to perform scientifically good research conflict with his obligations to his patient?

COMMENTARY

by PETER P. SORDILLO

The physician who enters a patient in a phase II trial of an anticancer agent has two goals: to evaluate the usefulness of the phase II drug* against a certain form of cancer and to offer the patient another chance after he has failed to respond to conventional chemotherapy. Occasionally, a patient in whom standard chemotherapy has not worked will respond to a new drug, and sometimes these responses are marked. Likewise, there is no way to assess the value of a new agent other than to test it on patients with cancer, since the effectiveness of a drug against animal tumors frequently does not correlate with its effectiveness against tumors in humans.

The case dramatizes the potential conflict between these two goals. Certainly, the physician does not want to expose his patient to a drug that is likely to make him sick but is unlikely to help him. On the other hand, the physician feels obligated to see that the scientific trials that he conducts are rigorous and valid so that it can be determined which of the hundreds of new drugs being tested every year are useful.

This conflict does not arise only when the "last" patient in a trial is to be treated, however, and cannot be resolved merely by ending the trial at an earlier point. Even after nineteen patients have failed to respond, by the criteria outlined in the case history, there is still a 5 percent chance the drug may be an active agent. Others have argued that it is a much greater error to conclude that a potentially active agent has no value than it would be to conclude that an inactive drug is active. The latter will be quickly discovered, but if a trial finds an active drug to be inactive, that drug may be lost forever. So even after 19 patients have failed to respond to a drug, the physician may feel he has not "proven" the drug inactive, and may be reluctant to end the trial. Further, even a hint of antitumor activity in such a trial may mean the drug has usefulness for a group that has not been tested (for example, patients not previously treated with standard chemotherapy) or in combination with other drugs. Conversely, even midway through a trial of a drug that has not produced responses (and most new anticancer drugs produce few or no responses), the physician may believe that this drug is *less* likely to benefit his patient than another drug that has not been tested.

Thus, the obligations of the physician to the patient and to do good research, may be in conflict not only when the "last" patient in a trial is being treated, but throughout the trial. Can this conflict be lessened? I would argue that whether a physician advises his patient to participate in the trial of a new drug must depend, both upon the status of the trial and the condition of the patient at that particular moment. For example, a physician may feel that a patient who is not healthy enough to live through more than one trial of a drug that proves inactive should not waste his "last chance" on a drug less likely to help him; thus he may recommend that the patient receive something else. On the other hand, there may be less objection to a patient who is expected to have a long life span being one of the last subjects in such a trial. Currently, these distinctions are not made. The toxicity encountered during the trial and the potential harm to the patient must also be weighed. The severe discomfort and the risk of serious infection that often accompany these drugs seem easier to accept early in a trial when there is still a significant hope of benefit than when the hope of benefit is small.

One might claim that imposing such conditions detracts from the scientific validity of the drug trial since we are "selecting" those patients who participate. While this argument may be valid for controlled trials, it does not apply to the noncontrolled phase II trials of experimental agents as currently conducted. The major purpose of these trials is to detect any sign of activity by a new drug, and the exclusion of sicker patients (who are less likely to respond to agents that are useful) could actually make it less likely that the drug will falsely be called inactive.

* A phase I trial attempts to establish the optimum dose of an agent rather than to assess its effectiveness.

Providing information on the status of the drug trial is clearly an essential part of giving informed consent. In current practice, what the last patient in a trial is told about the potential value of a drug is usually the same as what the first patient learns. But the information necessary to provide true informed consent must include not only a description of the drug's toxicity, but also some idea of the success or failure the investigators have encountered during the trial. This need not be a precise statistical statement, but something on the order of: "This drug has been very useful against animal tumors, although so far it hasn't worked on any of the patients on whom we have tried it. We'd like to try it on one or two more people with this form of cancer before giving up on it. If this drug doesn't work, we have other, newer drugs with which we can try to help you." A statement of this sort would provide the patient with some of the information he needs for deciding whether to take the new drug, without foreclosing the possibility that informed patients would agree to participate in these studies.

COMMENTARY

by KENNETH F. SCHAFFNER

Medical research represents a quest for useful *warranted* assertions about human beings and their illnesses. Over the centuries many therapeutic regimens of questionable benefit and often considerable harm have been inflicted on patients, from ancient enemeta and bloodletting to more recent gastric "freezing" for duodenal ulcers. Various statistical methods have been developed to test scientifically whether the observed effects of a new drug (or other treatment) are attributable to the drug and not due to chance, biological (including genetic and environmental) variability, clinicians' bias, a placebo effect, or spontaneous remission.

It will not be possible in this short commentary to discuss all the different designs for clinical trials, such as randomized, fixed sample, sequential, double-blind, matched pairs, and the like.* (The trial discussed here is what is termed a nonrandomized phase II trial.) Suffice it to say that all such trials have as their objectives *validity* or statistical soundness, *generalizability* or wide applicability, and *efficiency* or cost-effectiveness. In my comments I shall focus primarily on the issue of validity and its relationship to the ethics of patient care.

In part, because of biological variability, there are few completely deterministic processes or therapies that are 100 percent efficacious in medicine. In order to detect, in as rational a way as possible, those clinical procedures that might be useful, statistical reasoning must be invoked. A clinician who reasons statistically asks whether an observed pattern of patient responses can provide a valid inference for a clinically important effect at some level of probability. (Similar reasoning comes into play in the *design* of a trial.) Sound statistical methodology in a clinical trial is a sine qua non for grounded knowledge of the utility or disutility of a drug. A clinical trial of a drug that is methodologically unsound and/or statistically unconvincing will not persuade other physicians to use (or to discontinue) a particular drug.

Clinical trials, especially the large randomized ones, are essentially a post-World War II innovation. From their inception, investigators have had to wrestle with difficult ethical issues of patient assignment, risks and benefits, and more recently with the complexities of informed consent. Clinical trials also illustrate the ethical conflict of the physician as researcher and the physician as therapist.

Statistical validity and the ethical dilemmas inherent in medical research coalesce in this case study. The research physicians wish to be able to conclude with "95 percent confidence that the drug would be effective in less than 15 percent of patients with this kind of tumor, and thus that this drug has little usefulness against this form of cancer." They need one more negative response to achieve these percentages, presumably the patient in question.

Little information is provided about additional features of the research design or why the 15 percent figure was chosen. Apparently this is the control percentage for currently available therapy for this type of tumor in patients at similar stages of disease. The size of the trial needed to achieve the 95 percent confidence level (or analogously a significance level or P value $\leq .05$) can be obtained from what is known as a binomial distribution. To use a loaded coin-toss analogy, the investigators have asked themselves: how many times do I have to toss a coin, which I believe in the long run will turn up heads (therapeutic successes) less than 15 percent of the time, to be sure that I will get this result (<15 percent) nineteen times out of twenty (19/20 = 95 percent)? More specifically, if we assume a constant run of tails (therapeutic failures), how long must the trial be? The simple binomial formula shows that for eighteen failures the desired probability is = .054, whereas for nineteen failures, it becomes .045, thus crossing the "magic" threshold of "significance" or "confidence."

Significance levels of 5 percent or less and confidence regions of 95 percent or more have been adopted, often without question, by investigators and by journal editors who may not publish a trial unless the threshold is crossed. The 5 percent level is conventional but not completely arbitrary since in a normal distribution approximately 95 percent of the probability falls between +2 standard deviations from the mean. Still, some researchers, such as A. Feinstein, are critical of its dogmatic character.

These considerations underlie the case in question but do not provide any clear answer. Only additional information and ethical principles will provide the necessary guidance. The main ethical principle operative in this case—one accepted by essentially all investigators—is that no patient should be assigned to a trial if he or she and the responsible attending physician justifiably believe that harm will result. If there is another experimental drug available with more likely beneficial results, the patient should be advised of the option or options. If such a drug is not available, there is still a *higher* than 5 percent chance (actually 15 percent) that the drug currently under investigation will work in 10 percent of the cases. This chance is calculated on the basis of probability but should be adjusted to take account of other biochemical, physiological, pharmacological, and clinical information relevant to *this* patient. The attending physician should provide the patient with a summary of this complex and up-dated knowledge in terms the patient can understand. This summary should include a clear statement of the anticipated side-effects of the drug and a report on the efficacy of the drug to date. Should the patient elect the current drug and should it not work, the investigators will have achieved their 95 percent level, but clearly a patient cannot be expected to enter such a trial to achieve "statistical significance."

*The reader is referred to E.A. Gehan and E.J. Freireich's "Non-Randomized Controls in Cancer Clinical Trials," *New England Journal of Medicine* 290 (1974), 198-203; and more generally to H. Wulff's *Rational Diagnosis and Treatment* (Oxford: Blackwell's, 1976), esp. Chapters 9, 10, and Appendix; and to A. Feinstein's *Clinical Biostatistics* (St. Louis: Mosby, 1977). See also D.L. Sackett, "The Competing Objectives of Randomized Trials," *New England Journal of Medicine* 303 (1980), 1059-60.

6

Allocation of Scarce Resources

Dialysis for Schizophrenia: Consent & Costs

Recent reports have indicated that hemodialysis produces significant relief of symptoms of schizophrenia (H. Wagemaker and R. Cade, "The Use of Hemodialysis in Chronic Schizophrenia," American Journal of Psychiatry 134 [June 1977], 134). Hemodialysis is a method of treating patients with end-stage renal failure in which accumulated wastes in the patient's blood are eliminated by being circulated through a hemodialysis machine. The procedure takes from four to six hours, and in kidney patients, must be repeated several times a week. Before the patient can undergo this therapy, a shunt, or fistula, must be created surgically in the arm to provide access to the blood supply.

Investigators at the Clinical Center of the National Institutes of Health designed a protocol for a double-blind clinical trial to test the reported alleviation of symptoms in schizophrenics. The twenty subjects were to include men and women, ages eighteen to fifty, who had been diagnosed schizophrenic but were otherwise in good physical health and who were not acutely suicidal. The protocol called for the subjects to receive real dialysis treatments for ten weeks and sham dialysis for ten weeks. The symptoms in each of the periods would then be compared to determine whether the actual dialysis had any significant effect.

Conducting research with mentally ill people presents a number of ethical difficulties. For example, James D, a bright, twenty-seven-year-old single male, had been diagnosed a chronic schizophrenic. Although he was able to live in an apartment by himself while being treated with drugs, his symptoms of paranoia and hallucination remained. His psychiatrist referred him to the experimental hemodialysis treatment project.

At the time of his appointment, however, his parents appeared without him. They were informed about the dialysis project—its risks, discomforts, inconveniences, and potential benefits. They seemed enthusiastic and said that they would have their son call for an appointment. He did so and during this screening interview, he too was given extensive information about the research protocol. He received a copy of the consent form and was told to study it and discuss it with his parents. A week later he called asking to be admitted to the project. His father, who accompanied him to the hospital, asked the NIH admitting psychiatrist for more information about the dialysis and its risks; the staff repeated the information. While at the NIH, James D introduced his father to the other patients by saying, "This is my old man." In the meetings which followed, the father often furiously referred to this incident.

Two days later the father wrote a letter to the Director of the Institute stating that he was unwilling to have his son participate in the dialysis research program and that he would hold

the Institute legally responsible for any damage that might befall his son. All research activity on the patient was immediately halted.

Subsequently, at the parents' request, a letter explaining the project, along with a copy of the research protocol and the consent form, were sent to the son's psychiatrist. A meeting was then held with the patient, his parents, the patient's therapist, an ethics consultant, the unit chief, the ward administrator, and the research psychiatrist all present. The protocol was discussed again at length, as were the parents' objections to their son's participation.

During this and another meeting five days later, the father continued to withhold his approval, arguing that his son would not be able to bear the disappointment if the experimental treatment did not lead to a "cure." He admitted that he was not sure that his son actually felt this way. The patient then threatened to kill "my old man" if he continued to interfere with his life plans.

During these negotiations the hospital team continued to underscore the experimental nature of the project, the risks involved, and the right to withdraw at any time. At the end of the last meeting the father said that all of his questions had been answered, but for "personal" reasons he withdrew his consent for his son's participation. The patient was discharged from the project.

Did the staff act rightly in acceding to the father's objections?

COMMENTARY

by S. CHARLES SCHULZ

The question of whether or not this young man should have been continued in the research program rested on a fundamental ethical issue: was he capable of giving informed consent? He was an adult who had been living and working in the community on his own. He satisfied the Clinical Center's criteria for giving informed consent to research and hospitalization. He understood the project and its risks and was able to discuss it comprehensively.

Yet the patient was dismissed from the program because his father withdrew consent. Did the father withdraw consent because of a perceived slight by his son—being called "my old man"? Or was the father genuinely concerned that his son could not bear the disappointment of not being cured?

It is not altogether clear how the father came by this notion, or how real a concern it was for him. The father himself may have had difficulty sorting out the source of his information or intuition. Did it come from his son or from himself?

One could say that to have submitted to the father's threat of a court suit and not to have discussed the father's perceptions of the situation was not helpful to the patient. The most appropriate resolution would have been to clarify these difficulties with the patient and his family.

There is some literature suggesting that a hostile interaction between the father and son might have made the patient's lot worse.

In discussing the continuance or discontinuance of the patient's participation, it would have been important for the research group to examine countertransference issues and hidden agendas. Certainly, it would have been unethical to have included the patient in the program in order to allow ventilation of certain unconscious staff concerns about "tyrannical" fathers, or notions of grandeur about research intervention. If, however, the staff had explored possible unconscious mechanisms of its own, concerns about countertransference alone would not be a sufficient reason for discharging the patient. When a patient enters a research program with a hidden agenda, such as ending a commitment to another hospital, it is unethical to proceed with research until the issue is resolved. In this case there was no evidence for such a stratagem. As neither countertransference nor hidden agendas were of a troublesome nature, it would have been ethical to continue the patient in the project.

In addition, comprehensive and dynamically oriented clinical care of the sort that would have helped the patient and his family clarify their disagreements is essential to a sophisticated research program and the patient had a right to expect more such help than he received.

COMMENTARY

by DANIEL P. VAN KAMMEN

As physicians we have obligations to the patient, the patient's family, and the institution. These conflicting obligations lead to ethical dilemmas. Although he had psychotic symptoms, the patient indicated that he had given informed consent. He seemed to have approached the project realistically. However, his parents refused their support. Should the patient have continued in the research project against his parents' wishes?

The possible benefits of allowing the patient to participate needed to be weighed against the negative consequences. The possible benefits included a small chance that he might cease having delusions and other symptoms of his devastating disorder, and that participation in a clinical research project might have increased his self-esteem and independence.

What were the negative consequences? In biological and clinical research work with schizophrenic patients, it is assumed that family interactions play an important role in the patient's self-concepts and his relationship with other people. For the psychotic person to participate in an arduous research project with an uncertain therapeutic outcome, his support system needs to be taken into account, not only during the research project, but also afterwards. As a general policy, parents are invited, with the patient's consent, to the initial screening interview for the program.

On the basis of the original reports, it appeared that hemodialysis could provide, at most, only symptomatic relief in some patients, and only as long as they were on dialysis. But, a great deal of support is needed to make a reentry into society as a fully functioning member. A dramatic break with the patient's support system—in this case, his family—would not have been in his best interest. Thus, loss of con-

tinued support from his family would have had extreme consequences, especially if he did not get "better." The patient and his parents were very closely tied emotionally: he had a history of a persistent struggle with his parents, including his statement that he would kill his father if he continued to meddle in his life. The parents' interference ran counter to the patient's objectives of participating in the research project and his hope of independent living.

If the staff had aligned themselves with the patient against the parents—which is not an uncommon psychiatric practice—long-term negative effects upon the family unit might have occurred. If his father went to court the patient might have felt that a silent mandate was being given him to kill his father. On the other hand, the intense emotions of all parties did not preclude the possibility of the son shifting his position half-way through the project and becoming an agent for his father against the clinical-research staff.

Although secondary to the doctor-patient relationship, the psychiatrist as administrator also has an obligation to the institution and in particular to the research project. It was tempting to include this patient to get the project started. But legal charges probably would have led to interference in the project by a higher authority, which might have temporarily halted the project. Extensive time commitments defending inclusion of the patient would have absented the staff from the unit and interfered with both the research and the clinical responsibilities for research subjects, for whom dialysis is only one of the projects in which they could be participating. If the staff had had more extensive experience with the project, adversary relatives might have caused fewer problems. In any event, allowing the patient's continued participation would have created unacceptable stress to him, his parents, and the project, which was just beginning.

Because there was no concern about the adequacy of the patient-doctor relationship and the son's informed consent, the father's objections need not have been overriding. But the decision to participate in a research project of a novel and unproven treatment not only affects the patient, but also the institution and the patient's family. Long-term effects on all parties have to be taken into account. In view of these considerations, the staff was correct in discharging the patient from the project.

Editors' Note: Dr. van Kammen adds: "The study is now completed: eight patients finished the study. None improved. Several other studies not yet officially reported reach the same conclusions: hemodialysis is not an effective treatment for schizophrenia."

COMMENTARY

by JOHN C. FLETCHER

The preceding commentaries rest on an ethical principle that underlies most considerations in cases of this kind: beneficence. What will promote James D's welfare and reduce the chances of further harm? While the commentators differ on the outcome, their arguments focus primarily on the patient.

However, other issues are raised by this case and other ethical principles can be applied. First, is the physician's obligation to the patient surpassed by a higher obligation to the family and specifically to the father? The father's refusal to consent can be seen as a responsible effort to protect his son and other family members from disillusionment and further suffering, if the trial proves a failure. The father might reason that if the test results are significant, James can try dialysis later. Why should research psychiatrists be permitted to increase the distance between father, son, and family? To reason along these lines, one's ethical perspective would have to ignore legal definitions of the age of consent and James's referral by his own psychiatrist and would have to rest on a moral theory of obligation: respecting the father's responsibility and authority is a more important duty than seeking to promote the potential welfare of the patient by research.

Approaching the case with a theory of rights and specifically the patient's right to access, the argument flows in a different direction. James is an individual in need; he is equal with other individuals in need. Further, James is a patient with certain rights, among them the right to control his own decisions about medical care and research. His status as a psychiatric patient does not mitigate the claim that his autonomy and equality ought to be respected. The researchers in charge do not have a real conflict of duties, since the burden of proof against James's participation in research belongs entirely to the father.

If Mr. D's claim were accepted as plausible, then every parent could step between physician and patient regardless of the patient's age. Parental rights to intervene are overridden by the right of the patient to receive the best available medical care, assuming the consent of the patient. If James is prevented from access and the clinical trial has beneficial results for others, he would most certainly have a legal case for damages, based on justifiable claims of autonomy, equality, and fairness.

However, in addition to the patient's interests, this case raises questions about social justice and allocation of resources. Should this experiment be done at all in light of the present crisis in health care costs? Can the United States afford to treat with dialysis both end-stage renal disease (ESRD) and schizophrenia? Has sufficient "preventive thinking" preceded clinical trials of this technique? If the trials fail, we need to know the social costs of raising and disappointing hopes (one more time) about a "cure" for schizophrenia. If the trials succeed, we need to know whether the benefits can be fairly distributed.

The possible failure of the trial involves a judgment by schizophrenia researchers and those who allocate funds for mental health research. Dialysis for schizophrenia is now being attempted at possibly thirty to fifty centers. Except for the NIH project, none of these centers is doing a double-blind clinical trial. The social and emotional costs of failure are likely to be far less in the context of randomized clinical trials than in the context of uncontrolled trials.

The possible success of the trial can be analyzed empirically but its effects cannot be analyzed ethically without disturbing the propensity of American medicine to ignore costs. The money to treat schizophrenia with dialysis would not be "new," but would have to be drawn away from other goals and deprive other individuals of benefits, just as the payment

for treatment of ESRD by the federal government now consumes resources at an alarming rate. Roughly 40,000 such patients are now maintained in 900 centers with dialysis facilities or in home programs (only 13 percent of all patients). Kidney patients need three treatments a week (156 annually) at a cost of between $120 to $150 per treatment. The Institute of Medicine projects a cost of $2.5 billion for Medicare dialysis payments alone by 1985. In comparison the entire research budget for NIH is currently $2.8 billion, so one can easily see why present dialysis costs cause alarm.

What is the size of the schizophrenia problem? Approximately two million Americans (slightly less than 1 percent) are diagnosed as schizophrenic. Four million people will have a schizophrenic-like illness at some time during their lives. One half of all mental hospital beds are occupied by schizophrenic patients. How much would it cost to treat schizophrenia with dialysis? The average present costs would have to be increased by at least $200 per treatment because of the need for psychiatrically trained staff.

For the purposes of analysis, let us assume that an effective regimen required initial weekly treatments for sixteen to twenty weeks, followed by dialysis once a month on a continuing basis. Thus, there would be a maximum of twenty-eight dialyses in the first year followed by an annual series of twelve treatments. The costs of the first year would be $5,600; the costs of the second and succeeding years would be $2,400.

Assuming an average cost of $10,000 to construct one dialysis "station," it may cost $70 million to duplicate the present system that serves kidney patients. A safer estimate would be $140 million. If the present system that accommodates 40,000 kidney patients were duplicated, it could serve 300,000 schizophrenic patients in their first year and 600,000 in the second year and beyond. Then, total costs for the first year would be $268 million to treat 300,000 persons; total costs for the second and succeeding years to treat 600,000 would total $144 million.

A comparison of these costs with the most conservative estimates of the annual costs of schizophrenia to the nation ($11.6 billion), shows the benefit of dialysis—at least in terms of cost. And as technological improvements permit more flexibility for dialysis patients, there is likely to be more room for schizophrenic patients in dialysis facilities. Furthermore, because of the significant "downtime" in dialysis centers (perhaps one-third), large clinical trials of dialysis could be accomplished without any new construction.

This, of course, is only a thought experiment. There are no significant results yet from the clinical trials. Yet it is wiser, in my view, to conduct and pay for trials, even at the risk of disappointing hopes, so that potential expenditures of the size calculated here are planned only after the maximum test of the dialysis "benefits."

Who Has First Claim on Health Care Resources?

State Bill 529 calls for the establishment of community-based homes for the care and education of the mentally retarded. The bill provides one home for every fifteen persons presently institutionalized in four state institutions for the mentally retarded at a cost of $55.8 million. The estimated costs for the new care for the present population of 7,600 will be $70 million a year.

The bill was introduced by Representative John Sheehan who spoke in favor of it. He painted a dismal picture of antiquated institutions bereft of basic human necessities or amenities. Thousands of human beings, many unclothed, spend their days huddled in dark, drab rooms, where they are supervised by an overworked staff, many of whom have no professional training. Sheehan, who has the support of the parents' organization, the State Department of Mental Health, the local ACLU, and the religious leadership, concluded his case by pleading, "Justice requires that we extend this token contribution to these citizens, burdened by physical and psychological suffering, and by the degradation of our society's past inhumanity to its fellow humans."

Representative James Hudson and Dr. Robert Simmons, while emphasizing their concern for the care of retarded, spoke in opposition to the bill. Representative Hudson, noting that he was elected representative of all the citizens in his district, argued that he had an obligation to examine the alternative uses for the $14 million in additional funds called for by the bill. But first, he pointed out that the new total sum of $70 million equalled 1.5 percent of the state's budget, a budget raised by all its citizens, while the institutionalized population equalled only one-tenth of one percent of the state's population. The proposed increase of $14 million could buy hot lunches for all the state's school children; it could also provide job training for productive members of society. Hudson argued that the fairest thing to do would be to spread the money evenly among those who would be productive. "Our task as legislators," he concluded, "must be to serve the greatest good of the greatest number."

Dr. Simmons, as a physician, argued that the money could be used more efficiently in providing health care for three groups: normal or more nearly normal children (thousands of whom could be reached for every mentally retarded child), those potentially engaged in productive labor, and pregnant women. He showed that much mental retardation can be eliminated through prenatal diagnosis which he estimated to cost $200 per case for Down's syndrome compared to $60,000 for each institutionalized child. Even allowing that some of the institutionalized retarded might be gainfully employed if they were in high quality, community-based homes, the savings from spending the funds on detection rather than on more expensive forms of institutionalized care are enormous.

The legislative committee must now make its decision on the bill.

COMMENTARY

by JAMES CHILDRESS

We like to proclaim the relevance of ethics to policy. Certainly attention to policies rather than acts alone is critically important, and it may even lead us to see the continuities between moral issues in different areas of human life such as medicine and warfare. For biomedical ethics is the application of general ethics to one area of human activity. In this particular case, the perennial issues of distributive justice (determining who bears which burdens and receives which benefits) and efficiency come to the fore as in numerous other policy questions (welfare, for instance). But it is particularly vexing to try to rank social goods such as health care, education, and the environment. Paul Ramsey concedes that debates about such matters "are almost, if not altogether, incorrigible to moral reasoning," and that he does not "know the answer to these questions, nor how to go about finding the answer." At most the ethicist can only hope to identify and clarify some of the manifest and latent moral issues, arguments, and images in policy debates.

In this case, I do not think that the available information warrants an unequivocal endorsement of any of the options, much less the reasons for them. Although I would argue for policies to improve and extend the care and education of the mentally retarded, the various shortcomings that Representative Sheehan identifies (such as the lack of clothing and an overworked staff with limited professional training) would not necessarily be corrected in community-based homes. Despite the horrors of existing large institutions, smallness does not guarantee humaneness. Justice requires a significant (and not merely token!) contribution to the lives of the mentally retarded, but whether community-based homes are the most effective and most efficient ways of meeting their needs is a technical question. Policy depends on both technical and value judgments.

Representative Sheehan's appeal to the need for compensatory justice, based on society's past inhumanity, is hollow. It rings true only where the

members of some group like Indians and Blacks suffer the effects of earlier opposition (such as poor educational opportunities), but the mentally retarded as a group do not suffer from "society's past inhumanity" except when that "inhumanity" survives in present policies.

Representative Hudson's utilitarian motto is understandable as an indispensable policy consideration as well as political rhetoric. It remains merely rhetoric, however, unless there is some way to measure and compare intersubjective utilities (say, those of the mentally retarded and those of the productive members of society) in calculating the greatest good. Hudson's argument seems to be that justice (or fairness) is achieved by spreading "the money *evenly* among those who *would* be productive" (my italics). It is not clear why—in terms of this argument—a society should not favor certain productive individuals over other productive individuals if such an arrangement would increase the aggregate utility, instead of evenly rewarding and encouraging those who will probably be productive. Perhaps Hudson recognizes independent principles of justice instead of reducing them to utility. Especially puzzling is his stress on representing "all" the citizens, serving "the greatest number," and achieving a proportional relation between the size of the social group and its benefits. Such themes are not equivalent, and may even require different policies. For instance, fairness in representing all the citizens certainly on occasion permits a government to impose greater burdens on some than on others (as in military service) and to confer greater benefits on some than on others.

While Rep. Hudson assigns priority to social values other than the care and education of the mentally retarded, Dr. Simmons, assuming the priority of health care, urges a more efficient system that would concentrate on the detection and prevention of retardation. Doubtless some mix of detection-prevention and care is appropriate, but when the former fails, the latter is still essential.

Most of the arguments against State Bill 529, including Dr. Simmons', appear also to dictate a reduction of current expenditures for the retarded. If they preclude increased expenditures, they also require a reduction of current expenditures. But the optimal approach, from my standpoint, is to *increase* expenditures in order to overcome the gross inadequacies identified by Representative Sheehan (although it is by no means clear that the community-based homes will accomplish this end even if they realize other unidentified ends) while trying at the same time to implement a prevention program. Thus, we should not only continue existing programs for the care and education of the mentally retarded, but we should extend and improve them.

A simple cost-benefit analysis of policy, stressing effectiveness and efficiency, tends to truncate and even to flatten human values especially in its attempt to quantify decision-making. Without denying the importance of such an analysis, I think that symbolic and other values are relevant to policy-making and that the ethicist must point to them even when they resist easy quantification. The quality of our collective life depends not only on the ends sought and the consequences brought about (or avoided) but also on the values expressed. The care of the weak and vulnerable is among those values without which our lives would be seriously impoverished.

COMMENTARY

by JOSEPH FLETCHER

I would vote with Hudson and Simmons, against Sheehan. The reason for this basically is the principle that moral agents should seek to optimize the good and that the good is human well-being. The greater good of the greater number is the ethical standard of lawmakers and public servants in a democratic society. It is true, of course, that if a democratic society is humane and compassionate it will sometimes serve the interests of minorities, even at the expense—the considerable loss or cost— of the majority. But this will properly depend on whether the consequences of preferring the minority's good are tolerable to the democracy's sense of justice or fair play in the distribution of benefits. It would be wrong to follow a rule, such as that the weakest should be given the advantage or that "fairness" requires us to prefer the disadvantaged.

The claim of rule-based or doctrinaire moralists that to pass over the needs of the few has a brutalizing effect is false, on the record. Robert Louis Stevenson found that the Polynesians, amid the radically limited resources of their tiny atolls, practiced neonaticide precisely because they loved their children. Anthropology's and history's pages have other examples galore. This false argument, which is of the slippery-slope class, is ironically a consequentialist defense of a rule-based judgment; a false face to hide the real one.

In this case the best advice is that sacrificing the many for the few would only hurt the majority ("the common utility") without helping the unfortunate few.

State Bill 529 appears to be undiscriminating (simplistic) as to the psychometric levels and trainability of the retardates who would receive the $70 million annual outlay. Dr. Simmons' point about prenatal diagnosis is irrelevant, except insofar as the additional $14 million asked might be used to prevent the birth of retardates. (Some extreme doctrinaires would even oppose the selective abortion of prenatally diagnosed retardates.) The real question remains: what can and should be done for the ones that are born without or in spite of screening?

When Sheehan says "justice" calls for a "token" expenditure of public funds for the retarded or amented he must mean kindness or compassion; there is no injustice in the birth of such individuals when, as in the case of Down's syndrome, the condition is a chromosomal aberration without

malice or negligence. Only if prenatal diagnosis were carried out and a fetus actually known to be defective was brought to birth would there be an injustice—i.e., the witting victimization of an innocent party. In short, as things are there is only an inequality. In any case, justice does not call for tokens; it requires commensuration.

This comment is patently one of act utilitarianism, if we want to put a label on it. It makes its value choices according to consequences rather than rules or universalized norms, and according to the priority of the many over the few (unless the majority elect to forego their claims).

The Last Bed in the ICU

At the age of seventy, Mrs. A has been admitted to the hospital for the fifth time in as many years for treatment of respiratory difficulty. The last time she was in the hospital she had nearly died. She has severe emphysema, and when she developed a cold, her deterioration was so rapid that only artificial respiration in the emergency room saved her life. However, it proved very difficult to wean her from the respirator. She spent four weeks in the Intensive Care Unit and required constant care from the medical staff, principally Intern B. After she was discharged, she remained short of breath even while watching television.

Now, five months later, she has contracted another cold, but this time Intern B has managed to treat her without resorting to the ICU and the respirator. During her illnesses, Mrs. A's two sons have been in constant contact with the medical staff. They have been anxious, agitated, and demanding.

It is now 2 a.m. and Intern B is again called to see Mrs. A, who is becoming increasingly lethargic. It is obvious that she is in respiratory failure, and will probably die before morning if she is not given a respirator.

However, hospital policy requires that respirators be used only in the ICU, where the required supporting staff and facilities are available. There is only one bed open in the ICU. The residents like to save one bed for an emergency. As Intern B approaches, Mrs A's sons are waiting. He knows their questions: What's wrong now? What will you do?

What should the intern do? And on what basis should he make his decision?

COMMENTARY

by R. B. SCHIFFER

Mrs. A's sons, speaking for her, may ask for the respirator and ICU intervention. Should this request be granted?

There are a number of reasons why decisions concerning medical interventions for the seriously ill should be made by the patient, or by the patient's representative. But they do not apply in this case. Although Mrs. A's family has the right to refuse the ICU transfer and respirator, they do not have the right to demand it. Self-determination with regard to medical care is one thing, but a just allocation of scarce resources is another. The first right belongs to the patient, but the second is a claim which society makes upon the use of its health care resources.

Shall the physician decide? This would be an odd way to decide such questions (although in fact many are decided by physicians). Physicians, like families, have vested interests in some patients compared to others. And little in their educational background qualifies them as experts in the just allocation of scarce life-saving medical resources.

Still, I believe the physician has an important contribution to make. In this case, there is a single patient and an available, but costly, resource. We must first ask whether the scarce resource at issue *can* justifiably be used by the patient. We can separate this question from that of whether the resource *should* be so used. The physician might be in the best position to answer this first question.

Logically, there are two steps in deciding the allocation of a scarce medical resource for a seriously ill patient. The first is medical or clinical in nature; the second moral. The principle which guides the first step is usefulness: where there is no benefit, there is no obligation to intervene. Indeed, in a setting of scarcity, there may be a moral obligation not to expend resources from which a particular patient has no reasonable expectation of benefitting. The principle which guides the second step is that of justice: the fair allocation of scarce resources when not all who might benefit can be treated.

Suppose the family in the case had heard of the wonders of coronary artery bypass surgery, and demanded it for Mrs. A. This request would be denied for medical, and not moral, reasons. Such a procedure would be irrelevant for her, and would not improve her pulmonary dysfunction.

If it is the physician's responsibility to distinguish a useful from an irrelevant intervention, how should this be done? The case illustrates how difficult this problem can be. Is this woman medically eligible for the respirator/ICU intervention? Can we say that she has a reasonable expectation of clinically benefitting from this intervention? This I find a real dilemma.

Although medical eligibility is usually explained in terms of "usefulness" or "fruitfulness," it is difficult to find a clear statement of what this means clinically. An intuitive view of this concept might include the notion of an increased span of survival, that is, improved mortality. This view, however, raises the quality-of-life issue. The patient group for which these decisions are made are usually very ill. If the ICU machinery should prolong Mrs. A's existence, without clinical improvement, would we really describe her as having benefitted?

Is clinical morbidity, then, the yardstick by which we should measure usefulness? If the contemplated intervention in this case held reasonable promise of improving level of consciousness, or of restoring respiratory function, should we say that the patient is medically eligible without regard to questions of mortality? This seems odd as well. What if she also had a metastatic malignancy, which augured death in days to weeks? Under these conditions it would not seem that she was clinically eligible for the expenditure of a scarce medical resource.

If there are problems with either significantly improved mortality or morbidity taken separately, perhaps their *conjunction* should guide physicians in determining medical eligibility. That is, for a mortally afflicted patient to be medically eligible for a specific scarce life-saving medical resource, there should be in the responsible physician's judgment some reasonable expectation of significant clinical improvement in both mortality and morbidity. From the few details we know in Mrs. A's case, she does not seem medically eligible

for the ICU transfer, and it should not be offered to the family. Although her life span might be prolonged, there is no ground for expecting any significant improvement in her condition.

COMMENTARY

by BENJAMIN FREEDMAN

It is often said that questions of medical ethics fall into two categories: some concern procedures for decision, others the substance of decisions. The distinction, while intuitive, is not easy to sustain. How can we determine which procedures ought to be followed unless we know what values ought to be sought? On the other hand, what means are permissible in seeking to implement values?

The issue of procedure pervades the case of Mrs. A with five decision-making agents entering the stage, each with a special claim:

1. *The hospital* has arrived at a policy judgment that respirators may be used only in the ICU. The reason for arriving at this policy—that the necessary superstructure for effective use of the respirator is available only in the ICU—seems to be an instrumentally rational policy. For such a policy to be followed, what requirements ought to be satisfied? Clearly, the empirical judgment which dictated the policy should be supported by the best data and technical judgment available. We cannot be certain that this is the case here; "hospital policy" can be made by physicians, health-care personnel, hospital administrators, or other groups.

Even assuming that the best available empirical investigation has been heeded, two further questions for instrumentally rational policy arise. Are the means morally acceptable? Is the end desirable? Both questions are ethical in nature. If the end sought in the ICU regulation is the efficient use of respirators, we quickly smoke out value judgments lurking in factual language. What do we mean by "efficient"? Is efficiency to be sought at all costs? If there are no more respirators available than ICU beds, then it may make sense to limit their use to the ICU, but if additional respirators are available and a patient will die if one is not used, then the refusal to use one under less than ideal conditions seems morally questionable.

2. *The residents* "like" to leave one bed in the ICU open for emergencies. This preference has the flavor of something approaching a gentleman's agreement; for reasons which may be too obvious to require examination, a practice has developed. We often speak of some practice as our "policy." Yet this kind of policy differs crucially from more formal policies in that it need not have been, prior to establishment, publicly debated and announced. The unfortunate result is that what seemed not to require examination often turns out not to stand up under examination. In any event, "practice as policy" does not *bind* those adopting it. In contrast to other kinds of policies, informal agreements may be informally broken. The intern need not feel bound by it. He is an independent moral agent, and should evaluate both the general worth of this policy and the appropriateness of applying it here.

3. *The intern* takes policies of the hospital and the residents and finds himself bound to interpret them. As courts have occasionally acknowledged, interpretation of a policy is an act of policy making in itself. If for example, the intern decides against admitting Mrs. A to the ICU, giving as his reasons the policies of the hospital and the residents, he must himself have decided that Mrs. A's condition is not an emergency. In spite of the fact that without the respirator she will die, this decision could be acceptable—in the case when, for example, she would die despite its use. But without such a circumstance, the rights and wrongs of the matter should not be decided upon in the heat of action by the intern alone.

Some elements of the decision must be decided by the intern and/or his supervisors: Mrs. A's prognosis at the moment, for instance. But other questions would profit by more public examination in which invidious presuppositions, biases, and idiosyncratic views would, it is hoped, disappear. In this case the medical facts alone cannot tell us what is morally required. Even if the respirator will only prolong the patient's uncomfortable life, it is still a moral question whether that prolongation is of sufficient value that the treatment is morally required or permissible.

4. *The relatives* may wish to be involved in, and not merely informed of, the decisions being made in this case. Certainly the relatives' wishes should not necessarily be definitive in deciding what should be done in this case. If the agents responsible for hospital policy (rather than just the intern) decide that treatment that will only prolong life in a diseased state does not qualify one for a respirator (either in or outside the ICU), and if the patient and family are made aware of this before entering the hospital, their views about treatment should not override that policy. Furthermore, the script, curiously, has left out the main protagonist. What are Mrs. A's views? If she is totally unable to communicate, the relatives may have a more significant place in the decisions, but if she is able to communicate and there has been no formally announced hospital policy against treatment in her case, then surely she should have some say in the matter.

5. *The patient* has been in this situation before. Has any effort been made to uncover what she feels about the aggressive efforts made in the past to maintain her in her morbid state?

Assuming that we may find out—possibly from the relatives—Mrs. A's wishes, I believe those ought to be respected. At worst, this would put her in conflict with the intern's individual judgment that her case does not constitute an emergency. A person's right to treatment should not be invariably subject to a physician's opinions, even when those opinions are based upon a mixture of medical and value judgments. It may be true that only a physician can assess the weight of the medical factors; it does not follow that the physician will do so correctly. If we must err, let us err on the side of individual dignity and autonomy.

The larger moral is that no quick delineation of policy in the heat of a medical crisis is likely to prove adequate for solving moral problems.

Forced Transfer to Custodial Care

Mrs. B, seventy-four years old, has diabetes and is partially blind. She has lived in a nursing home for the past ten years, and the state Medicaid agency pays her expenses. She feels secure in the home, and she has made many friends there.

The state is trying to save money by caring for its elderly medical patients at the lowest possible cost. Many patients are being transferred from nursing homes to less costly facilities that basically offer only custodial care. The goal is to move as many patients as possible out of facilities providing inappropriately intensive medical support to institutions offering maintenance meeting state-approved standards of quality, but without the medical services now deemed unnecessary.

An arbitrary grading system has been established to evaluate nursing home patients to determine their suitability for transfer. Patients are assigned a certain number of points according to their ability to dress, feed, clothe themselves, and the like. If the number of points the patient receives is higher than a designated total, officials feel that the patient can be transferred without any harmful effects.

When she is evaluated, Mrs. B receives more than the designated number of points, and the decision is made to transfer her. She is not consulted, nor is she given a voice in the decision. She is simply moved—forcibly and against her wishes—to a custodial care institution. The evaluation does not take into account the psychosocial impact of the move or the personal dimensions of Mrs. B's adjustment to the home she had been in for the last decade.

Is the state's conduct ethical? Since it is paying the costs of care, and since it has assigned a higher priority to other areas of medical care for funding, does it have the right to disregard individual patients' wishes concerning the location of their care?

—Lawrence Hessman

COMMENTARY

by CHARLES FRIED

This case is sad and appealing, but raises no difficult questions of principle at all. Presumably the nursing home from which Mrs. B would be moved is deemed inappropriate to her care because it provides a more intensive level of medical supervision than she requires. And, obviously overall costs of any program cannot be contained if a patient's friendships and preferences require that that patient continue to occupy space in a medically more intensive (and therefore more expensive) environment than is medically indicated.

The situation must arise fairly regularly with patients who would be more comfortable in the more pleasant, caring, and competent surroundings of an acute care hospital than in a nursing home. Surely, however, to be moved by such considerations and thus in effect to turn acute care hospitals into nursing homes would make the present disastrous situation regarding hospital costs even worse.

The state agency has to do what it is doing (assuming that it is doing what it is doing intelligently and fairly). If it did not, then some portion of its limited health care budget would be wasted, and persons with more acute needs would be inadequately treated. In other words, if Mrs. B were to win, we must assume that there would be losers in even more desperate straits than she is.

Of course nothing requires the state to act without consulting Mrs. B nor hearing her side of the case. But this is not the same thing as giving her "a voice in the decision." Competing beneficiaries of limited funds would of course all love to have a "voice in the decision," when that means giving them a veto over unfavorable decisions. Mrs. B should certainly be able to present her case and to explain why either an exception should be made or why the state agency's guidelines when applied to her case do not require that she be moved. But to allow the matter to depend on her choice is preposterous.

Of course her physician should make every *proper* effort to have her remain in those circumstances which are most favorable to her. He should make sure that the appropriate agency is aware of the extent to which a move might be detrimental. But it is no part of his duties as her physician to falsify the facts (as doctors sometimes do in efforts to procure certain governmental benefits for their patients) nor to use irregular pressures on her behalf. It would be wrong for a lawyer —and it would certainly be wrong for a doctor—to do this. In the end, if the state agency does move her, the responsibility is not her doctor's but that of the agency. It is no more his responsibility than would be the decision of the Social Security Administration to deny a disability benefit when a patient's doctor was unable in all honesty to come forward with a diagnosis justifying such benefits.

COMMENTARY

by ROBERT MICHELS

Institutions make decisions that affect the lives of individuals and may affect them adversely. When this occurs (as it did with Mrs. B), we must ask whether it was "ethical," whether it should have happened, and, if not, what should have been different.

This case is simple enough. Mrs. B is old, sick, disabled, and lives in a nursing home. Yet life is not all bad; she feels secure and has many friends. The state is paying her bill, and the state wants to save money. For administrative reasons it wants to move her, judging that she is "suitable" for transfer to a cheaper setting. Against her will, and without her participation in the decision, she is moved.

The case is sad as well as simple. On the face of it, it should be otherwise. Mrs. B

should be allowed, at age seventy-four, to finish her days where she feels happiest. State-supported nursing homes are hardly palaces, but this one is Mrs. B's home, and the state should forcibly remove a citizen from his or her home only under extreme circumstances. True, it is paying the bill, but one of the marks of a civilized society is that even dependent citizens have rights and privileges.

However, that is not the whole problem. Health care is expensive, and the resources allocated to it force us to make choices. Perhaps if Mrs. B stays in the nursing home, a young man with asymptomatic hypertension will not be detected by a screening program, or a slum child with cerebral palsy will not have two weeks at a summer camp, or the Methadone Maintenance Center will have one fewer social worker. These are the real effects of budget cuts and reallocations.

What are we to do? Mrs. B earns our sympathy, but the needs are greater than the resources. Somewhere choices must be made. Are cases like Mrs. B's the inevitable result? Are there ethical guidelines as to how the choices should be made?

First, the question of resource allocation cannot be ignored. The public must constantly be reminded of Mrs. Bs as it decides how much should be devoted to health care and how it should be distributed. It might be that the state should not be forced to choose between Mrs. B's life and other alternatives, but that citizens should support, or demand, that it provide all of them, sacrificing other goals in the process. But the recent trend of political decisions has not been in that direction.

Second, there are guidelines that should apply to state decisions that directly affect the lives of individuals. The state is planning a transfer of patients from one institution to another, but Mrs. B is an individual who lives in her home, and the state's procedures should recognize that to one who lives there, institutions are homes and each individual is different.

The decision-making process should be able to make individual decisions about individuals, not simply apply "arbitrary" systems of classification. The noxious character of institutions stems from their tendency to classify people arbitrarily rather than to respond to their individual needs and desires. Further, Mrs. B should be able to participate in the process—in fact, her participation should be required. This is part of recognizing that she is a person, not a line on a state budget. Finally, the state's guidelines should take into account the meaning of the move to Mrs. B, as well as her physical capacity to adjust to it. There are at least two reasons for this: the less important is the clinical fact that her ability to function in the new institution is largely determined by the meaning she attaches to going there. The more important one is that she is a person, and to consider her physical capacity without concern for her psyche is to treat her solely as an organism.

It would seem that the state fell short on several of these, and, therefore, was "unethical." However, we should recognize that the state might have followed ideal procedures and reached the same conclusions, forcibly wrenching Mrs. B from her home, if its citizens have other priorities that are higher than the care and comfort of the needy.

COMMENTARY

by STEVEN SIEVERTS

One would wish that this pathetic case were purely conjectural, but alas, it reports a scenario which has played many times in the past few years. The imperative of health-care cost containment has become excessively dominant in some government agencies, seemingly overriding all other considerations. All too often, the Mrs. Bs have indeed suffered as a consequence of how some public administrators have behaved under that kind of pressure. Cost-cutting, when it becomes obsessive, can offend human decency.

From an ethical standpoint, however, I suggest that the issue in this case is misrepresented. The question is not whether the Medicaid agency has the right or obligation to assure that beneficiaries are receiving at public expense only appropriate services to which they are entitled under law. Clearly it has both.

Rather, the issue is the unacceptable manner in which the state officials and the health professionals seem to have behaved in this case and in other cases like it. The Medicaid law and the state regulations simply do not instruct bureaucrats to force our nurses and social workers to carry out sudden and inhumane transfers of elderly poor patients without any prior consultation. They also do not require the negligent public administration and professional management that kept this patient in too intensive a facility for a decade, not only wasting money but probably making her more dependent and less self-reliant than was necessary. They do not force procedures that ignore common decency.

This case presentation asks: since (the state) is paying the costs of care . . . does it have the right to disregard individual patients' wishes on the location of their care? Let us ask the question another way: do individual citizens have the right to receive, on demand, publicly financed services to which they have no entitlement? The answer, when it is phrased that way, seems clear: obviously not. Any health insurance program—public or private, categorical or universal, limited or comprehensive—must employ procedures to assure that beneficiaries receive only that to which they are entitled.

Those of us who are health care administrators and those of us whose jobs involve the financing of medical care have a constant obligation to assure that our front-line personnel do not implement necessary policies in ways that trample on patients' rights and sensitivities. This requires clearly written policies and rules as well as sensitive management. In this case, the ethical issue may be in part that the public administrators' instructions to the social workers and nurses in the field may have been so poorly phrased (or poorly intended) that insensitive or brutal behavior was subtly encouraged. The crux of the matter, however, is that health care professionals charged with a demanding task—arranging for the timely and humane transfer of a patient to a more appropriate facility (or finding a legitimate and appropriate alternative course of action)—chose to behave in a way that violated not only basic standards of civilized human behavior but also strongly established ethical principles governing how health care professionals are to act with respect to patients.

If the law or the rules tend to promote unethical behavior, it is an ethical obligation of the administrators and professionals to get them changed—and failing that, to interpret them humanely and even to ignore or disobey those aspects that violate basic principles.

The state regulations were indeed badly written, but that is not the main issue. The central point is that the administrators at

the top and middle, and the professionals who actually deal with patients, have an overriding obligation to care about the welfare of those patients. When the implementation of rules, even stupid rules, is done in ways that deny basic human rights, such as the right to be consulted and heard about one's own health care, primary blame must be affixed on the people responsible for that implementation, not on an impersonal "state."

Refusing an Amputation: Who Should Pay for the Extra Care?

Otis Simmons, a fifty-eight-year-old derelict, walked barefoot in bitter cold through the streets of Manhattan shortly before Christmas, in order to reach Roosevelt Hospital. "I froze," he said later. "I sat in one place 15 hours." After he was hospitalized, he developed gangrene in his badly frost-bitten feet. The doctors wanted to amputate the infected portions, noting that otherwise the condition could become "life-threatening." Simmons refused the treatment: "My two legs got to stay on. I won't have the operation. I got to cure my own self."

Soon after, despite objections from hospital physicians, a State Supreme Court justice ruled that Simmons was legally competent and had the right to refuse the amputation.

Antibiotic treatment helped to stall the infection. However, Simmons finally lost two toes on his left foot and part of his right foot. The bill for his three-month hospitalization amounted to $29,000 and has been submitted to Medicaid. A hospital spokesman has said, "We don't know how much they will pay or when they will pay it."

Assuming a competent patient has the right to refuse medical treatment, does he have the right to have Medicaid funds pay for additional care required by the refusal?

COMMENTARY

by WILLARD GAYLIN

We have been dealt a bad hand. Anyone who would stand against Otis Simmons puts himself immediately into opposition to that grand tradition of rugged individualism so highly respected by modern American culture. One might just as well take on John Wayne, Billy Martin, and Kojak (three symbols, come to think of it, I wouldn't mind tackling.)

Mr. Simmons, a derelict with dignity, demands the right to take his own risks and suffer his own consequences. The result—in the limited amount of data presented to us—seemed to place him not in the category of a crank, but of a medical conservative. He postpones surgery, preferring antibiotic treatment, until such time as partial amputation is ultimately necessary. It is true that this cost the taxpayers $29,000. On the other hand, it seems like a bargain when compared with the $16,000 bill (exclusive of special nursing and physicians' fees) presented to a friend of mine for a seven-day hospitalization. Hospital bills these days seem to bear no logical relationship to services rendered. Mr. Simmons acted within his rights.

Having said all this, a problem remains. Sooner or later, we are going to have to confront the relationship between autonomy and responsibility in health care. "Responsibility" is not a fashionable word these days; "rights" is the preferred language of current moral discourse. I have never viewed "rights" and "responsibilities" as essentially contradictory or mutually exclusive concepts; others do.

"Rights," of course, refers to two distinctly separate concepts: being left alone, and a claim against the government. It is specifically that latter interpretation of rights that is going to demand a reevaluation of responsibility. Claims against the government inevitably demand limits; limits demand comparisons; and forcing consideration of a just distribution of resources—I suspect—will lead us once again to the concept of personal responsibility.

The current popular concept of autonomy—autonomy without responsibility—is at best a peculiar one. I think specifically of a colleague of mine who is evangelical in the defense of adult autonomy. An adult ought to have the right to ride without seat belts, if he so prefers; to purchase any dangerous drugs at his own risk; and, it goes without saying, to commit suicide; in effect, to be the total executor—even a bad one—of all of his interests, provided he causes no harm to others. At the same time, this same colleague is outraged at the idea of penalizing in any way a person whose reckless irresponsibility leads to his own illness. This champion of autonomy argues that it is absurd, for example, to penalize the cigarette smoker, since that is to assume that he has some voluntary control over his smoking. This strict autonomist, it seems, is at the same time a psychic determinist in the manner of the early Freudians.

This peculiar concept of autonomy without responsibility strikes me as identical to the early adolescent's view of independence. "When it comes to decision-making, I am my own master; the consequences of my behavior had best be handled by my parents." This view ignores, among other things, the fact that the knowledge that one must pay the piper becomes a significant factor in determining our behavior—unconsciously motivated as well as volitional behavior.

There are also those of us who believe that the concept of an "individual" is meaningless independent of the community that supports his very being as a human. To elevate autonomy to a point where the state legitimates self-destructive and dehumanizing behavior also defines the quality of the state. While the paternalistic state can be a tyrant worthy of dread, the "indifferent" state, by ignoring the biological and sociological concept of "community," can be equally destructive. Beyond that, in a time of limited resources, where spending a dollar in one area inevitably will mean *not* spending it in another, we have transcended the bounds where autonomous behavior ceases to impinge on the rights of others.

By considering the subject of personal responsibility, we immediately enter that dreaded bioethical locale, the "slippery slope." If the cigarette smoker is responsible for his cancer, is not the obese, the

obsessive worker, or the physically inactive responsible for his heart attack? There is, I submit, a distinction between ordinary and extraordinary risk, direct responsibility and indirect responsibility. In questions of voluntariness the law has a long-standing, respectable expertise in drawing those distinctions. So have we all. If one believes in the moral right to abortion—and I am not here arguing that point—one can still see the distinction between abortion for a diabetic tendency and abortion for Tay-Sachs. In the latter, there is a greater urgency, a greater predictability, and a greater responsibility. Similarly, we ought to be able to begin to draw distinctions along lines of responsibility for our own health—not to the point of excluding forgiveness and decency, care and kindness; not to establish a pariah stature for the "offender," but at least to begin to introduce penalties and prices that encourage responsibility to oneself, to others, to the community. At a time of scarcities, when one person's irresponsibility may deprive someone else of health care, the question of autonomy takes on new meaning.

COMMENTARY

by CHARLES FRIED

Medicaid must pay. This conclusion bothers me, but I do not see how it can be avoided. The best way to understand it is to see it as an example of a general point: indigency does bestow certain immunities that people with resources do not enjoy.

It is quite clear on the facts as given that it would have been improper for the medical authorities to perform the amputation against the wishes of the patient; and I also have no quarrel with the court's conclusion that the refusal of the amputation was not in and of itself a proof of incompetency. To deny Medicaid reimbursement could only be justified on one of two grounds: (a) that Roosevelt Hospital should itself bear the cost of Simmons's hospitalization, or (b) that once Simmons refused the amputation he should have been discharged and denied further care. If Roosevelt Hospital acted properly in this case, there is no more reason it should end up without reimbursement than in the case of any other indigent with an expensive ailment. So there is no reason to expect the hospital to absorb the cost.

Did the hospital act properly in incurring these expenses? Since I assume that it could not have performed the amputation against Simmons's will, to say that it acted improperly must mean that Simmons should have been discharged when he refused the recommended course of care. Moreover, to say this commits one to the conclusion that no other hospital should have admitted him after such a discharge, since a successor hospital would just be in the same position as Roosevelt Hospital was in initially. And that would mean that having refused the care, the only proper course for a hospital (*any hospital*), the only course that would not result in a charge against its own resources, would have been to allow Simmons to die without further care. This is absurd. Therefore, I conclude that what Roosevelt Hospital did was proper, and that it should be reimbursed.

This conclusion becomes more acceptable when we realize that it is forced upon us principally because of Simmons's status as an indigent. If Simmons had been a person with resources, then a private insurer (or for that matter a government insurer) would quite properly have treated Simmons's choices as inappropriately increasing the cost of his care, an increase for which no coverage was provided. This would be viewed as a kind of uninsured option that Simmons could make, but at his own expense. If Simmons had been a wealthy bachelor with no dependents or relatives, nothing would be more reasonable than to charge him for the additional cost of his care. If he had had dependents, presumably they could put pressure on him not to deplete resources to which they might have some claim; but if they did not succeed, then he would still be required to pay the excess out of his own pocket.

The problem, therefore, is only difficult because he has no resources. It seems unfortunate that he should be able to cast such burdens on the public treasury, but the same situation would obtain had he attempted suicide, or become ill because of alcoholism or excessive cigarette smoking. And I do think it would be appropriate to charge higher health insurance premiums or to demand larger contributions from persons with selected, bad health habits—smokers, for example.

7

Public Policy

Laetrile: Cancer Cure Or Quack Remedy?

Glen L. Rutherford, a Kansas resident, had suffered from chronic rectal bleeding for about eighteen months. He was treated for diverticulosis and then referred to Dr. J. Walker Butin, a gastroenterologist at the Wichita Clinic, in the fall of 1971. A sigmoidoscopy indicated a large polyp. After a biopsy was performed, the clinic's referral laboratory diagnosed the specimen as "invasive, well-differentiated adenocarcinoma"—in other words, cancer. Mr. Rutherford was advised to have an operation, and was told that removal of the anus, rectum, and part of the lower colon might be necessary. His doctors felt that the lesion should be curable if surgical removal was performed.

Convinced that surgery meant death, Mr. Rutherford failed to report for the operation. Instead, on December 21, 1971, he went to the Centro Medico Del Mar in Tijuana, Mexico, for examination. There he was treated with Laetrile. In five days the bleeding stopped, and by the fourteenth day a sigmoidoscopy showed that the growth had shrunk from the size of an orange to that of a grape. Surgeons then cauterized it. He returned to his home and job and he has had no recurrence of his illness.

At the Del Mar clinic, he had been receiving intravenous injections of amygdalin, pancreatic enzymes called "Wobe-Mugos," and Laetrile enemas — substances not approved by the FDA for sale in the United States (see box). During a subsequent checkup at Del Mar, the chest X-rays showed a doubtful nodule in the left lung, the rest of the studies were negative, and a barium enema showed no rectal tumors. He was advised to continue a daily course of B_{17} pills and Wobe-Mugos enzymes.

Under U.S. law, Mr. Rutherford cannot directly purchase Laetrile and bring it back to this country from Mexico or have it shipped to him for preventative treatment of his cancer. The Food and Drug Administration has never made a clear determination of the efficacy of the drug, although the McNaughton Foundation, whose head is a major manufacturer of Laetrile in Mexico, had applied in April 1970 for such a decision. The FDA's regulations make it impossible for an ordinary person to have an application for review of a new drug such as Laetrile processed so that the agency would either approve or disapprove it.

When Mr. Rutherford's underground supply was cut off by government action against his supplier, he brought suit in the United States District Court in Oklahoma "individually and on behalf of a class

composed of cancer victims and their spouses, who are responsible for the costs of treatment . . . seeking an order directing the Federal Drug Administration to desist from precluding the administration of vitamin B_{17} or Laetrile to patients in the United States suffering from cancer."

Mr. Rutherford and the other victims of cancer argue that they are being denied freedom of choice for treatment by Laetrile, and that they are being deprived of life, liberty, and property without due process of law guaranteed by the Fifth Amendment.

The government's view, on the other hand, is that Laetrile, while harmless in small dosages, does not have the anticancer properties its adherents claim for it. If it is legalized and promoted as an anticancer agent, it will divert patients from more conventional therapies that may help them.

Should Laetrile be freely available to patients who want it?

COMMENTARY

by DAVID W. CRIPPEN

Recently, a nationally syndicated columnist defended the use of Laetrile for cancer therapy by a most unusual argument. He argued that, even though the best evidence we have shows that Laetrile is worthless in the treatment of cancer, the public should have the "right" to buy and use it simply because it is the "right" of the individual to fritter away his money, or even his life, should he desire to do so.

This is a fascinating argument that transcends all scientific debate over the cold realities of research data. Should individuals in a free society have the right to choose unproven treatment over conventional therapy as a point of personal freedom? I would like to argue that they should not have this freedom of choice and I present the following support for my argument, not in terms of scientific data but from a psychodynamic point of view.

In our society, we have defined limits over which the freedoms of the individual may not extend. The freedoms of the individual are subservient to the rights and ultimate well-being of the group. Thus, I may not yell "fire" in a crowded theater and call it freedom of speech. If we, as responsible physicians, allow demonstratably ineffective drugs on the market without a fight, a great number of people who simply don't know any better will get worthless, expensive hoaxes instead of effective treatment. I submit that this situation impinges on the rights of the group to have the best medical care available such that some individual freedoms of choice must be stifled to avoid it.

It is unfortunate but true that the lay public are *not* intelligent, informed consumers when it comes to health care. They do not have the expertise to evaluate critically drugs or methods of care. Like it or not, they are at our mercy. *Someone* has to take the responsibility for outlining what is reasonable and proper treatment or we'll all be up to our ears in snake oil. Of all the available sources of information concerning health care, we, as physicians, are the best bet for the unknowing public.

If we shirk our responsibility, we will be in competition for care of patients with those whose motivations are questionable at best. If we allow Laetrile on the market, we will also confer on it a certain respectability. Promoters of Laetrile would like nothing better than to be able to say, "Of course, Laetrile is effective. Do you think the public health officials would allow it on the market if it wasn't?"

Quack remedies are very attractive to a large portion of the public. Laetrile, in particular, satisfies at least two classical criteria for "quack remedies." First, it's expensive. The drug itself is cheap to manufacture, but the actual treatments bring whatever price the traffic will bear. People tend to measure effectiveness by cost. The more you pay, the more it's worth. Second, its proponents imply, if not flatly state, that physicians are suppressing a cure for cancer so that they may continue to profit from its treatment. Superficially, this sounds absurd, but we must remember that a great deal of the public regard us as arrogant, ostentatious money-grubbers. This argument is also appealing to those who feel that they have been treated coolly and impersonally by physicians.

Laetrile is promoted by entrepreneurs and manipulators who carefully cultivate the interest of people who have nothing to lose and everything to gain. The general public can't appreciate the esoteric facts of research statistics. What they do understand is anecdotal reports of "miracle cures" and, in essence, hope—a hope we cannot give, many times, in good faith. We, as physicians, are not equipped to compete with carefully constructed promotion campaigns and we cannot dispense false hope. The only equalizers we have are tough regulatory laws.

If we are remiss in our responsibility to legally fight unproven remedies, the finger will eventually point back at us. We knew better and yet we did nothing as innocent people delayed effective treatment for hoaxes. We contributed to the respectability of worthless drugs by our laissez-faire attitude.

Of the two alternatives we have, the continued illegalization of Laetrile and other unproven drugs is clearly the lesser of two evils.

COMMENTARY

by ROBERT M. VEATCH

Glen Rutherford appears to be the victim of the technologizing and professionalizing of health care in our society. He has found a treatment

course he believes is controlling and perhaps curing his cancer, yet he is unable to get access to the material because of intervention by technical medicine's gatekeepers. The anecdotal clinical evidence from the case might lead one to believe that the Laetrile is effective in Mr. Rutherford's case. It is extremely dangerous, however, to reach such a conclusion on the basis of a single case without a controlled trial. Although the FDA has refused to permit some research on the effectiveness of Laetrile, there have been a few studies. One, conducted at the Sloan-Kettering Institute for Cancer Research, found that the drug helped inhibit the spread of breast tumors in mice. Other National Cancer Institute-funded studies, however, failed to confirm these results. I am, therefore, going to presume for purposes of this discussion that the Laetrile is, in fact, ineffective and that Mr. Rutherford's apparent cure is a spontaneous remission. That will make it much more difficult to defend his right of access. Nevertheless, even under those assumptions, I believe that this right can be defended.

There are two principles that might be used for resolving this dilemma. Both of them seem to me to lead to the conclusion that even if the drug is ineffective, it ought to be obtainable by a person such as Mr. Rutherford. First, the case could be approached in terms of the classical ethic of the physician, as seen in the Hippocratic Oath, that we ought to take the course of action that will be most likely to benefit the patient. That seems to me to be the more difficult case to make for Mr. Rutherford's right of access. After all, if we have assumed that the drug is ineffective and are told by physicians involved in the case that immediate surgical removal of the lesion was called for, encouraging Mr. Rutherford to have the surgery would seem to be the course that ought to be pursued.

Certainly encouragment of surgery is justified but there are some serious problems, however, with the ethical stance that we ought to require the patient on Hippocratic grounds to have this surgery or even to encourage him by means of eliminating his right of access to the drug. The first problem is that the ethic of the Hippocratic tradition is an ethic explicitly for physicians, and it is the FDA, that is, an agency of the federal government, and not a medical group which has restricted Mr. Rutherford's access to the drug. Even if the medical profession as a whole were convinced that it would be more beneficial for Mr. Rutherford to have the surgery rather than the Laetrile, it does not immediately follow from that that the FDA should prohibit access to the drug frowned upon by the medical profession. In fact, however, a number of physicians are supportive of Laetrile use or at least willing to permit individuals to choose its use. Reportedly 800 physicians are members of the Committee for Freedom of Choice in Cancer Therapy, a group supporting access to Laetrile. Sixty of these physicians are permitting disclosure of their names for referrals of patients who want to use Laetrile.

We should confront the argument directly, however. Is banning access to such a drug really the course that is most beneficial for the patient? If we are to estimate potential benefits and harms to the individual, we must consider all benefits and harms. It should be conceded that banning access to Laetrile might encourage some people to have more orthodox treatments for their cancers, but we have no evidence that that is the case with Mr. Rutherford. On the other hand, we must include in our calculation an individual's extreme agony when he believes that there is a drug which will cure him of cancer but cannot gain access to the drug. The outlawing of Laetrile in the United States has generated a blackmarket complete with illegal border smuggling and outrageously inflated prices corresponding to the risks necessary to make the drug available. Both the psychological and economic costs are tremendous. Furthermore, there appears to be no evidence of any harm being caused by the Laetrile (except the indirect effect of diverting some individuals from more orthodox therapies). If Mr. Rutherford is not likely to undertake the orthodox treatments, it seems reasonable to conclude that the ban on Laetrile is, at least in this case, doing him more harm than good. This is arguing the case in traditional Hippocratic terms.

Laetrile has been surrounded by legal and medical controversy for over twenty years. Now a pharmacological component has been added to the debate. British researchers report (*New Scientist*, July 15, 1976) that the substance smuggled into this country as an anticancer agent may not be Laetrile at all.

Although the names Laetrile, amygdalin, and Vitamin B_{17} are often used synonymously, there is confusion over whether they really are identical. The process patented in 1953 by Ernest Krebs, Sr., a physician, and his son Ernest Krebs, Jr., a biochemist, for the manufacture of Laetrile from apricot pit kernels specified a two-stage process. In 1973 Tom Connors and Angus McLean in Great Britain succeeded in replicating the first stage of the process but not the second.

Connors and McLean claim that no one has produced Laetrile in quantities sufficient for proper clinical assessment. Then what is being used as Laetrile? They believe that what is being distributed as Laetrile is really its precursor in the manufacturing process—amygdalin.

The claim that the original compound called Laetrile destroys cancer cells is based on its ability to release a cyanide component that attacks an enzyme that is present in abnormally high amounts in certain human tumors. Amygdalin is a structurally similar but chemically different substance, and it does not have this cyanide-releasing property. However, even if the anecdotal reports of cancer cures are based on the use of amygdalin, it is conceivable that this substance has some other, unknown, anticancer properties.

It seems likely that the controversy will continue unabated on all fronts.

That is not the only basis of arguing a right of access, however. Mr. Rutherford in his court case emphasized much more of the principle of liberty or self-determination. Mr. Rutherford is quite literally being deprived of liberty and property, and possibly life itself, by the prohibition. If the principle of self-determination is the basis for a policy decision it would appear that Mr. Rutherford ought to have the right of access, independent of consideration of benefits and harms. Even if it could be shown that he was likely to accept the orthodox treatment if Laetrile remained illegal, from the point of view of the principle of self-determination he still ought to have the right to have the drug.

Clearly liberty is not without limits. Serious harm to the public interest certainly justifies infringements on individual liberties. It seems ludicrous, however, to suggest that there is an overwhelming public interest in the banning of a drug which has never been demonstrated to be harmful. Even assuming that it is a useless drug that occasionally diverts people from orthodox therapies, it is nonsense to argue that there is any overwhelming common good at stake. The individual has the right to refuse any medical treatment whatsoever, even one guaranteed to cure him of a fatal illness. Along with that right he must certainly retain the right to take a drug he believes to be effective even if the rest of society does not share that belief.

In fact, the Court ruled in Rutherford's case in August 1975, that since the FDA had abdicated its duty to make a clear determination on Laetrile, Mr. Rutherford's complaints were justified and he and the seventeen other plaintiffs in the suit are entitled to import the drug. The FDA appealed the ruling, but it was upheld in October 1976.

In an action which may be repeated in other states, the Alaska legislature last spring passed a law that makes it illegal for hospitals and health centers to stop doctors from giving Laetrile to patients who request it.

Does this mean that the FDA should permit the drug to be freely distributed in the United States and that it should have no further interest in the matter? The answer is yes and no. I can see no reason to restrict access to drugs—at least those which are not likely to produce harm to others, such as methamphetamine or alcohol might, and are not even likely to produce direct harm to the individual taking them. That still does not mean, however, that the FDA should have no rule. The FDA is responsible for labeling of drugs sold in the United States. If it, on the basis of its best investigations, is thoroughly convinced that the drug is useless, it has a clear obligation to require very prominent labeling to that effect. If an individual wishes to take a drug the FDA has labeled useless, that ought to be his legal right. If he can offer good reasons for taking the drug then he may be morally right as well.

Interns and Residents on Strike

March 17, 1975 marked the beginning of a four-day strike by the members of the housestaff organization, the Committee for Interns and Residents (CIR), against the League of Voluntary Hospitals in New York City.

When the strike became imminent the chief resident in a major medical center in New York was faced with a conflict. He viewed his role primarily as that of a person responsible for providing quality care to the patients in his hospital, the person who knew the strengths and limitations of all the housestaff working on his service. This meant constant surveillance of charts and procedures, as well as daily examination of those patients who, in his opinion, were at a stage of their treatment when close senior supervision was necessary. He felt that if the housestaff were absent during a strike, his own presence would be crucial to the continued good care of those patients in the hospital. He considered this facet of his role to be that of patient-advocate in the short run.

But, as chief resident, he felt he had another important role as well—that of advocate for the housestaff. He agreed with a great many of their complaints and believed that in some cases their hardships did affect patient care. Interns were working all day and all night, and were frequently being asked to go on working until rounds at the end of the second day. Every third night this schedule was repeated. There was also no doubt that interns and residents did perform so-called "out of title" work to give their patients the best care possible. Such work included transporting patients to X-ray because there were only two escorts in the entire hospital, or delivering emergency specimens to the laboratory because the night messenger either could not be located or could not be counted on. There was also no doubt that these tasks did take the physicians away from the patients' bedsides and exhausted them further. Some senior physicians made little of these complaints and often said they had "had things much worse" when they were housestaff. But this response solved nothing.

The chief resident felt the housestaff's complaints were for the most part valid, indeed that they demanded attention and discussion, and deserved adequate solutions. And he felt this aspect of his role to be that of patient-advocate in the long run, for these issues would affect patient care over a period of time.

Thus, there were two important components to his sense of duties as chief resident, each vying for the whole from opposite sides of the picket line. Short-run patient welfare stood in conflict with long-range patient welfare. To what extent would this strike help solve the issues being addressed, or was it merely a political tactic on the part of a growing housestaff organization seeking to establish itself nationally? Most importantly, which suffering could he live with more easily? For there would certainly be either short-term suffering resulting from a one hundred percent walkout, or longer-term suffering if existing conditions were perpetuated or allowed to deteriorate further.

COMMENTARY

by ROBERT M. VEATCH

The chief resident struggled with his conscience, weighing plausible arguments for both alternatives. I think that a good case can be made for the physicians who chose to strike. I believe that is the judgment I would have made. The decision hangs, at least in part, on the ethical principle standing behind the physician's choice.

One thing seems clear: it is almost impossible to justify the strike in terms of the ethic of the traditional Hippocratic physician. That ethic is hyper-individualistic, holding that the physician's primary, indeed his sole, moral duty is to do what he thinks will benefit his patient. Of course, a house officer could argue that the strike would benefit his particular patients on the floor at the time. But that seems implausible. The Hippocratic physician even in the modern period seems never to have faced the dilemma of trading off one patient's interest against another or of compromising the patient's interest for some other good: for his family, for the state, or for the physicianless poor. This may well account for organized medicine's relative indifference to the social dimensions of health care.

The strike forces us to come to grips with the traditional individualistic, patient-benefitting ethic of physicians. Such a principle, taken literally, would mean physicians have a duty to ignore the physicianless. We cannot continue to ignore long-term social impacts, viewing medicine entirely in terms of individual interactions. Insisting that the physician should do what he thinks will benefit those who are his particular patients at the present time is not only paternalistic and individualistic, it is also an oversimplified reduction of a complex set of social interactions. It defines the situation improperly.

The physician must consider long-term effects of perpetuating poor health care when he makes decisions on the short-term interests of his patients; how then is he to ignore those

larger considerations when deciding whether to strike for conditions that could better that care?

The problem is in deciding when those compromises of the patient's short-term interests are justified. There is of course a special obligation to present patients, an obligation stemming from their present need and from the implicit promise or contract to render care. But that promise is not without limits. When a patient releases the physician from responsibility, that physician has not only the right but the obligation to stop doing what he thinks will be beneficial to his patient. Sometimes (but not always) the long-term interest of other patients or the physicianless must justify short-term compromises as well.

Clarification may be found in the principle of justice or fairness. If a physician can significantly serve the interest of those whose suffering is or will be much greater—the least well-off—he could consider that the primary responsibility to his present patient is waived; the implied contract carries this qualification. The obstetrician is justified in not keeping a routine appointment with a prenatal patient if another woman has entered labor, conceivably even if the person desperately needing help is not also his patient. Serious needs of others are an understood exclusion in the patient-physician contract.

The critical difference between the obstetrician's abandonment and the striker's is that the obstetrician has a specific patient's needs in mind while the striker does not. While giving priority to needs of specific, identifiable individuals over more general and unidentifiable needs is understandable psychologically, that is not inherent in our sense of justice. The principle of justice warrants the special attention to those who are or will be least well-off even if they cannot be identified specifically and immediately.

If this principle of justice is the basis for justifying the strike, not simply any set of benefits to others justify the abandonment; it would require showing substantial benefits to others who are or will be particularly less well-off. For this reason the strikers should make arrangements for emergency coverage of critically ill patients and emergency cases. If, and only if, the beneficiaries were or would be in a worse position—say those who now receive no medical care at all—would the strike be justified. This I think justifies a strike without letting the justification collapse into a crass utilitarianism. I am not sure this theory of justice was actually the reason behind the strike, but it seems to me to be the most plausible justification for it. The alternative defense, based solely on the greater total good to patients in the long run, is an argument open to the strike defenders, but it is a dangerous one.

I think the physician strike is justied for a second reason, a reason less rooted in ethical principle. The strike has a humanizing quality on the image of the medical profession. House officers were interested in reducing hours on duty not only because they thought it would benefit patients in the long run, but presumably because they did not find the hours pleasant. I see nothing wrong with recognizing that even physicians have interests other than their patients'. It seems to me helpful for the public generally to recognize that physicians are humans who have needs and desires of their own, families needing their attention, and life goals outside of patient care.

Sociologically one of the characteristics attributed to a profession, as opposed to an occupation, is that it is supposed to be "collectivity-oriented"; that is, a professional is not supposed to show self-interest, but be committed to the interests of others. The physician strike, insofar as its goals are the physician's own interests, may provide a healthy dose of moral realism. It makes us realize that it is both inevitable and acceptable that professional people serve their own interests as well as those of patients. The strike, in addition to forcing physicians to deal with more social moral claims such as the claim of justice, also makes us see them as real human beings.

COMMENTARY

by DAVID BLEICH

Much can be said for the positions of all who were affected by the recent hospital strike: the administrators, the physicians, and the patients. There is an old rabbinic anecdote which seems very much apropos to this situation. Two litigants came to the rabbi to settle a dispute. After listening long and patiently to the plaintiff, the rabbi said to him, "You are in the right." Then he listened with equal attention to the defendant and said to him, "You are in the right." The litigants departed, highly pleased, but the rabbi's wife, who had been listening to the proceedings, was puzzled. "How is it possible," she asked, "that they should both be in the right?" The rabbi pondered the question long and deeply. Finally he turned to his wife and said, "Shall I tell you something? You are also in the right!"

The chief resident presents a very strong case in support of his striking colleagues. He also confirms the visceral reaction of countless numbers who instinctively feel that it is immoral for a physician to abandon a patient. Both positions are "right" because both the physician and the patient present compelling claims. As is so often the case when balancing moral obligations, what is needed is not a decision with regard to right and wrong but, rather, the establishment of an order of priorities within a hierarchy of values. Both are right, but one is more right than the other.

Society refuses to sanction strike action by policemen and firemen because interruption of the vital services performed by these civil servants might result in the breakdown of the very fabric of the social order.

In imposing obligations and exacting services is society guilty of tyrannical imposition of its own selfish interest upon certain classes of its citizenry? Clearly a plea of "not guilty" can be sustained only if individuals possessing such skills and bearing such responsibilities do in-

deed incur unique moral obligations. Society may legitimately advance and enforce such claims only if there does exist a correlative moral obligation on the part of the individuals from whom these services are demanded.

Man is a social animal; he is also a moral creature. Man intuitively perceives a social morality which leads to the recognition that man *is* his brother's keeper. Men feel themselves to be reciprocally obligated to preserve the life, safety, and well-being of fellow members of the human community. Human society has long recognized that unique obligations devolve upon certain of its members by virtue of their talents, training, and/or unique responsibilities. A swimmer who blithely ignores the plight of a drowning person acts in a morally reprehensible manner. "You shall not stand idly by the blood of your fellow" (*Leviticus* 19:16) is the Scriptural formulation of the ethical imperative which mandates life-saving intervention. Not all men share equally in this responsibility. Obviously, a nonswimmer cannot be required to plunge into dangerous waters; his efforts would be futile at best. But, in a life-threatening situation, surely a skilled swimmer is morally bound to place himself at the disposal of his fellow man. Enhancement of skills brings in its wake a commensurate increase in moral responsibility.

Moral responsibility is readily perceived in the context of direct, proximate, causal relationships. Obligations in less proximate situations are not at all obvious. For example, is a person obligated to develop life-saving skills so that he can succor others in time of need? Certainly, acquisition of such skills should be encouraged and is surely deserving of approbation. But is it incumbent upon any given individual to acquire such skills?

Society as a whole may well be obligated to train lifeguards and post them at public beaches, but no individual need necessarily feel obliged to make this profession his life vocation. The training and deployment of policemen, firemen, lifeguards, etc., in *anticipation* of potential emergencies, is a societal rather than an individual obligation. But subsequent to completion of training and acceptance of responsibility the members of these professions do assume personal obligations.

A similar distinction may be employed in resolving dilemmas arising from conflicting moral duties. May a person on the way to a class in first-aid instruction ignore the plight of a dying man, on the plea that he must perfect skills which may enable him to rescue a greater number of persons at some future time? Our instinctive response is a clear-cut negative. No person may plead that an activity designed to advance future societal benefits is justification for ignoring an immediate responsibility. Immediate needs create immediate obligations. Anticipated needs do not generate immediate, compelling obligations. The "here and now" test is a general rule of thumb which may be applied to most situations requiring an ordering of priorities.

Physicians possess skills which are not shared by other members of society. In accepting hospital appointments they agree to make their skills available to those whom they serve. Hence society has a unique claim upon their services and they, in turn, bear a unique responsibility to society. It is not legitimate to shirk an imperative moral responsibility to patients requiring medical attention "here and now" on the plea that present nonfeasance will ultimately redound to better care for more patients at some future time. An immediate moral claim cannot be set aside in anticipation of future claims which do not as yet exist.

The physician may quite properly refuse to perform "out of title" tasks provided such omission does not jeopardize the patient. Similarly, elective procedures which may be deferred without harm or risk do not pose an immediate obligation and may be postponed for good and sufficient reason. But, under no circumstances, may the real and immediate needs of a patient be ignored.

To be sure, society has an obligation to train and post lifeguards. *A fortiori*, it must build hospitals, train a sufficient number of physicians, and provide adequate health care facilities. At the same time, society has an obligation to the physician as well. Health resources should be allocated in a manner which does not place an undue burden upon either the physician or other members of the health care professions. Society should create conditions which will enable the physician to discharge his duties without hardship to himself. As members of society, we are obliged to use every legitimate means to effect such changes as may be necessary. However, the fact that society has been remiss in providing optimal arrangements does not relieve the physician of his moral obligation to the patient who is in need of his services "here and now." Strike action under such circumstances, while understandable, is nevertheless morally unconscionable.

Baby Making and the Public Interest

A thirty-two-year-old California woman, Joan Travis, and her husband, David, had tried for over two years to have a baby. After seven months on a fertility drug, Mrs. Travis became pregnant and thereafter gave birth to six infants at Santa Clara hospital. The delivery was normal, but none of the babies survived more than eight days.

Mr. Travis participated in a group health insurance program through his employer. The policy normally pays for delivery and medical care of newborns, and the insurance carrier paid the hospital bill, which came to more than $50,000.

The cost of the delivery and subsequent care will cause an increase in premiums to all members of Mr. Travis's group health insurance plan next year. Because it is a joint employer-employee program, both will share the burden. His employer plans to pass on the additional cost by raising premiums. Nevertheless, Mrs. Travis maintains that she will take the same drug again in another attempt to have a child. Do the Travis's have a moral obligation to avoid taking a risk which would increase the insurance premiums of Mr. Travis and his co-workers? Does the insurance company have a moral obligation to pay the costs for the voluntarily assumed risk? Does every couple have the right to bear children, regardless of the cost to society?

COMMENTARY

by THEODORE TSUKAHARA, JR.

Group health insurance operates on the principle of risk pooling. Premium rates are based on the average risk profile of the group membership rather than on the specific risks faced by particular members. The scope of benefits, the size of the group, and the demographic characteristics of the members are factors which influence the premium calculations.

The inclusion of maternity benefits in a group policy is usually very expensive, especially if there are significant numbers of younger members in the group. The probability that maternity claims will be made against the insurance pool is very large. Thus, premiums paid by older members will reflect the higher risk of maternity claims even though the likelihood that they will require this coverage is very small. The economic effect is that older members bear part of the medical costs of younger members who will become parents.

In order to establish some measure of equity in access to the group insurance pool, normally some limitations are imposed on benefit payments. Typically, medical claims which arise from a previously existing medical condition will be subject to some restriction. For example, most policies would exclude payment for infertility treatment on that principle. Because individual decisions can affect the risks faced by individuals for particular benefits, it is important to include restrictions in group policies where the premiums are not tailored to risks individuals are willing to assume privately. Otherwise, some individuals will overconsume benefits and cause a real transfer of resources from others to them in the form of higher premium payments for all.

Most group health insurance programs recognize that the decision to have children is properly viewed as a private choice. To provide full insurance coverage for maternity-related medical expenses would give couples with a strong desire for large families an economic incentive to exercise their preference at the expense of couples with opposite tastes. Therefore, most policies attempt to be neutral and to provide coverage only for complications which arise from pregnancy which requires extraordinary medical intervention such as surgery. Maternity coverage is thus limited to the incremental costs over the amount required for a normal delivery. However, the Travis's insurance program did cover care for newborns and the company had a legal obligation to pay the hospital bill.

Joan and David have exhibited an intense desire to become parents. I assume their initial decision to undergo treatment for infertility was made after a complete discussion with their physician about the risks associated with the drug. In particular, I assume they were fully aware of the potential for multiple pregnancies and the associated reduction in the probability of survival of any newborns; I assume further that David was aware of the limited coverage provided by his group insurance program. Their decision to proceed without additional insurance indicates their willingness to accept the full psychological and economic costs of their decision.

In spite of their tragic losses, Joan and David are determined to try again to become parents. Even if the insurance company was obligated to make payments the first time, there appears to be a flaw in the group policy which must be rectified in order to protect the other members of the insurance pool from another large outlay on behalf of the Travis's. The policy must be rewritten.

In economic theory the absence of insurance for a risky choice is an example of market failure. The usual

remedy is for the government to provide the required insurance. Thus, if Joan and David cannot insure against the possible financial losses which may result because no insurance is available, then economic justice suggests that they be assisted in coping with any financial losses that might arise. If insurance is available and they choose not to insure, then the Travis's should be responsible for any financial consequences resulting from their decision. They could argue that they could not afford the premiums. This information, however, should signal to them the magnitude of the risks associated with their desire for a child. Since Joan and David stand to gain directly from the joys of parenthood, they should also be prepared to bear their fair share of the costs.

COMMENTARY

by SEYMOUR SIEGEL

The case of Mr. and Mrs. Travis involves one of the basic human rights —the right to bear children. This right is an integral part of our humanity, an expression of the innate desire to perpetuate the race and to somehow mitigate the threat of our mortality. The cry of Rachael (Gen 1:28)—"Give me children or I will die"—is a poignant expression of the fundamental importance of children to human existence. This consciousness is being altered in some circles today. However compelling the arguments concerning the threat of overpopulation, the shortage of economic means, the liberation of women—the basic thrust of human nature to contribute to the future remains powerful.

One of the purposes of governments and communal organization is to protect basic human rights. Governments are instituted among men to help us pursue happiness. There is no doubt that for the vast majority of mankind the opportunity to bear children is indispensable for the pursuit of happiness. Therefore, the community has a responsibility to make responsible parenthood possible.

In our age of astronomical medical care costs, governments and the community have the responsibility to assure that parents can have children by guaranteeing that financial needs in connection with the birth will be met. There is no sure way of knowing in advance the precise amount of these costs. Some parents will require less; others much more. An insurance plan is a contract in which all parties involved are obligated to help the other individuals in the agreement to realize their legitimate health goals.

It is clear that the Travises will not be able to realize their aspiration to be parents unless they can have some assurances that economic barriers will not prevent their having children. It seems that their plea is: give us some assurance that if there are inordinate charges related to the birth of our children, we will be helped to pay, or we will have to forego the right to have our own offspring. It seems to me that the fellow insurees of Joan and David Travis have the responsibility to make it possible for all the members of the contract to have children—even where circumstances result in extraordinary costs. These costs will, to be sure, involve an additional burden. But this is part of the price we pay for our living together in community.

This case is paradigmatic of the problem of individual rights against the demands of the community. This is especially important in the light of the increased demand that births be limited in response to the growing population problem. There is, of course, great merit in the efforts to limit the number of births in the world. However, the individual who wishes to have children does have the right to assert his privilege even against what is perceived by many to be the world's needs for population control. This does not mean that educational efforts trying to persuade people of the danger inherent in unlimited population growth should not continue. But it does not mean that no form of coercion, including economic coercion, should be applied.

The human birthright includes the right to give birth. The desire for propagation is one of the elementary forms of our humanness. To thwart this desire is to endanger something that adds to our human stature. As in many other instances, to do the good involves costs. However, I believe in this instance it involves a cost we should bear without bitterness, and even with good cheer.

Regulating an Anti-Aging Drug

Thomas Lockhart is the president and chief executive officer of Lockhart Pharmaceuticals. His company has been doing basic pharmacological testing on a series of compounds attempting to identify an agent that will affect the basic processes of aging.

In its early work the company tested procaine analogues, vitamin E, BHT, and a series of other compounds reported to have life-span-extending properties. They found, however, that the most promising was a compound that would be marketed under the trade name of Sinemort. The drug would be very inexpensive to produce, and promises to be a money-maker for the company as well as, in Lockhart's view, a great help to mankind.

The compound has proven promising in animal testing, and Lockhart is now considering human trials. In fact he himself has been taking the drug on an experimental basis and is enthusiastic about its promise. The drug being tested is already marketed for use in humans as an anti-depressant. Although it has not been widely used for this purpose because there are other, more effective drugs available, the compound has been demonstrated to be safe in humans at dosage levels above those contemplated in the clinical trial. In fact it has been found safe for use in children.

Lockhart is working with Wilson Jeffers, his medical director, to prepare the IND (investigation of new drug) application for the Food and Drug Administration. They have reached the point where they have to list the possible harmful effects of the drug. According to Jeffers, the side effects are mild, rare, and immediately reversed upon discontinuing the drug. Dr. Jeffers remarks jokingly, "We could say that the drug will also change the lifestyle of the population, increase the size of the labor force, bankrupt the Social Security Administration, create new and unknown family relationships, possibly make the country more conservative politically, and make drug-taking routine from puberty on."

The FDA is charged with evaluating potential risks and benefits before approving an IND and eventually establishing that the drug is safe and effective before approving it for general use. It is staffed with pharmacologists and lawyers to review applications.

Should Lockhart Pharmaceuticals be obliged to include the social, political, and life-style risks of their drug in the IND application? If not, who should take on that task?

COMMENTARY

by SIDNEY CALLAHAN

As usual, in debates over bioethical questions one issue concerns *who* should decide possible risks and benefits; in this case, who should control the anti-aging pill? There is also the substantive problem of *what* ought to be decided: should we legitimate anti-aging medication?

In answer to the first question, I can see no justification for leaving the decision solely in the hands of Mr. Lockhart, Dr. Jeffers, or the FDA's pharmacologists and lawyers. Ethical and social decisions that will affect the general public for better or worse should not be decided by a few persons whose training and interests may be very narrow.

Nor would the problem be solved by hiring an in-house ethicist who could give a Good Housekeeping seal of ethical approval, in case the consumers complain. One ethicist does not guarantee wisdom. It is equally hopeless of course to look for guidance from "the people" or the mythical man in the street.

In such a dilemma, I think, important bioethical decisions should be put before an appointed interdisciplinary group of persons specifically charged with considering the ethical and social ramifications of medical technology. (The National Commission for the Protection of Human Subjects is a prototype.) This group should include many who have had extended ethical training in different traditions.

But once the group is created, the problem remains: what should they decide about anti-aging research? If called to testify, I would say, "Let's go ahead with this work for the following reasons based on the following affirmations."

My first affirmation is that it is good to live and bad to die. Life, like pleasure, health, and plenty, is a good thing; and death, like pain, disease, and poverty, is an evil to be avoided. My second affirmation is that technology, rationality, and science are both liberating and essential. The fact that technology has been misused does nothing to deny the great benefits that it has brought to human life, from irrigation to vaccines.

The objections offered against the anti-aging pill in this case do not seem convincing. Changing American lifestyles and reorganizing the labor force and the Social Security Administration are long overdue items on the nation's social agenda. I also doubt that increasing the age of the population will automatically make the country more conservative; instead it will create a force to struggle with discrimination against the aged, one of the last unacknowledged prejudices.

As for the problem of making drug-taking routine from puberty on, surely that tendency already exists. Who among us doesn't already depend to some degree upon caffeine, alcohol, soft drinks, tobacco, marijuana, vitamins, and aspirin? Mild antidepressants, from wine to a spot of tea, have relieved human anxieties for a long time.

A more serious question and difficulty would concern the way in which the drug worked. If it simply prolonged life after

deterioration was extensive and succeeded only in producing chronic debilitation, there would be little progress. To be a real anti-aging agent it would have to produce a higher level of vigor for a longer time. This version of the drug would be better named Convital rather than Sinemort. Another important factor would be whether its action was continuous or discontinuous. Would one age suddenly, as did the natives of Shangri-la when they left the valley? Some might still choose a sudden decline, but others would not.

The availability and distribution of such a drug would raise other ethical problems. Surely it would be unfair for only the rich to have access, since they already live longer and look younger. The question of how family patterns would be changed is also a serious ethical concern. While it would be wonderful to live longer and know one's forebears and descendants, it would be disastrous to have one's children take the pill first, especially if it slowed down the whole maturation process. The prospect of living out a present lifespan while still supporting one's slowly aging dependent children would produce a new kind of oppression.

The overall trend in evolution has been to delay human maturation, but at the same time the life expectancy of the parenting generation has also been extended. The empty-nest period could be seen as the reward of the increased social and economic investment in rearing children.

It is well to remember that the objections to anti-aging research have been raised about every technological change in history. After all, the neolithic revolution in agriculture also increased the life span, changed life style, changed the family, and created a lifelong dependence upon the daily intake of an artificially created substance, that is, food from agriculture. Surely there are problems in managing progress, but we can be hopeful about the abilities of humans to cope. For one thing, with the successful introduction of anti-aging measures, we will all have a lot more time in which to think.

COMMENTARY

by JAMES F. CHILDRESS

The question "who should control the anti-aging pill?" is subordinate to the question "what ought we to do about this possible technology?" The answer to this second question depends on "technology assessment," which, as William James said of pragmatism, is only a new name for an old way of thinking. Technology assessment, as Joseph Coates has argued, is an "art form," not a science.

Any technology assessment may have different implications at different stages of decision making. Consider three questions that might be asked. First, should we give research on aging or on some specific anti-aging technology high or low priority in the allocation of public resources? Second, should we conduct or permit research on human subjects in order to determine the safety and efficacy of a technology? Third, should we prohibit, allow, or control the implementation, distribution, and use of a technology? We could, for example, decide not to fund research on aging but to permit research, implementation, and use of any technologies that are developed. The ethical and public policy issues may vary at these different stages.

The third question, which is important in this case, cannot be answered without examining the probable positive and negative consequences of anti-aging technology. The consequences indicate why this technology is or should be a matter of public interest. While our society has not yet provided a high quality of life for the elderly, society's failures can be distinguished, in part, from such quality-of-life factors as power and vigor of body and mind. An anti-aging technology could increase the length of life (1) with an increase in the period of physical and mental vigor or (2) without an increase in the period of physical and mental vigor. While the Lockhart Company assumes that Sinemort will be "a great help to mankind," it does not mention the quality of life that individuals whose lives are expanded can expect. To retard the aging process without an increase in the period of vigor would hurt rather than help. All the problems of quality of life that the elderly now face would be extended, and the broader social problems of caring for health and welfare would be dramatically increased.

Let us take the category emphasized in the National Academy of Sciences report, *Assessing Biomedical Technologies:* "Longer life with parallel increase in vigor, i.e., an 'addition' of extra years of vigorous maturity without any increase in the period of adolescence or decline." Suppose that these extra years could be provided easily (for example, by drug rather than by diet or discipline) and inexpensively. While such a prospect is no doubt very attractive for most of us, its overall social consequences may not be so attractive.

What about the positive consequences? For the most part, they are very speculative. Albert Rosenfeld argues that if we extend the life span, people will then have the motivation to care about what happens to posterity; it will be in their self-interest to do so since they will be around long enough to experience the consequences. And Zhores Medvedev suggests that if the life span were longer, "People might savor it in less haste, and perhaps with more altruism." Such speculations feature the language of possibility—what might happen—but it is very difficult to base public policies on such flimsy possibilities.

What about the negative consequences? Some commentators fear that people would be less willing or able to carry out projects with "alacrity and promptitude" since they would not feel the pressure of time and impending death. Others fear that people would be less willing to take risks—survival would be more important since people would not want to risk so many years of life. The result could be stagnation, or a society of control.

In the light of these speculative consequences, what should we do? We do not yet know enough in this area to override the presumption in favor of inquiry, research, and commercial implementation. Yet public controls and regulations are in order. Lockhart should be permitted to proceed with carefully controlled research on human subjects and controlled implementation that would be monitored so that the society could make necessary adjustments as it learns more about the aging process and the effects

of anti-aging technology on the quality of life and society. Regarding social impact, the possibility of negative effects on social security, and so on raises important caution flags, but societies and conditions do change, for better or worse. Hence, we should develop policies that keep options open. In this scenario we are not yet at the point where prohibition is justified.

Lockhart should include social risks in its application and FDA should consider these broad effects. But the public's participation in the assessment of anti-aging technology is indispensable and should be maximized through public hearings, publicly funded workshops, and congressional hearings.

Drinking on the Job

Boyd Anderson was a company man. He started working at Tone Master Radio in 1945, just as it was beginning to expand. Over the next twenty-five years the company became a huge conglomerate. Anderson worked his way to the top, becoming vice-president of the western division in 1970.

Shortly thereafter the company brought in an aggressive young president to revive lagging sales. He lasted only a year, but in that time he replaced Anderson and transferred him back to the company's main office, where he was given only limited responsibilities, a small office, and a part-time secretary.

Anderson had become accustomed to meeting clients at lunch and having a few drinks. When he had to face the humiliation of being useless to the company, he began to drink more heavily. He lobbied for new positions within the company but failed. Month after month the mail brought only rejection letters from other firms. His drinking became more and more uncontrollable.

Offered a minor overseas post with the firm, he refused it, in part because his family was not able to go with him, but largely because he was afraid his drinking would become known. By this time his self-confidence was gone. The company had been his life, and it was clear that his career was over.

In 1973 at the age of fifty-eight he was told to accept special early retirement. Within a month he was found in an alcoholic convulsive coma. He went through several episodes of drying out and drinking again. Nothing worked.

At this point he sued the company for $1.1 million for retroactive medical disability, claiming his job had made him an alcoholic. He claimed not only the disability pay, but payment of his medical and psychiatric expenses and back pay. He argued during a hearing, "My God, you give your life to the company, then you discover that they think you're washed up. The mental strain is just too much. Drinking was part of my business life. The company should bear the responsibility."

What kind of responsibility, if any, should the company bear for Anderson's drinking problem? If it is not found legally liable for his expense, does it still bear a moral responsibility?

COMMENTARY

by HERBERT FINGARETTE

Insofar as Anderson's problems were caused by his excessive drinking, he is morally responsible for them. He should also be legally liable for their costs unless he is specifically insured.

Until he was demoted, Anderson voluntarily accepted his company position, including (presumably without protest) the custom of luncheon drinks. Over a period of many years he drank at lunch without drinking to excess.

What changed things? The company president reassigned him to a less important position. Understandably, he was unhappy. He then began drinking excessively. Plainly, it was the demotion and resulting unhappiness that were decisive in triggering his excessive drinking, not the long-established custom of drinking at lunch.

Can Anderson reasonably justify his claims against the company? He can claim that his alcohol abuse was job-related. But the risks and damages at issue here are not specific to a particular job. They are risks associated with working for hire generally —one risks being demoted or fired, either of which is likely to make one unhappy. So Anderson's drinking is not "job-related" in any specific way that would entail company responsibility or financial liability. After all, an employer cannot be held responsible for keeping an employee happy or for the untoward consequences of the imprudent actions of an unhappy employee.

Anderson could try to base his claim on the fact that he is an "alcoholic," that "alcoholism" is a "disease" that he acquired while on the job, that his self-damaging behavior is a "symptom," and that therefore he is not responsible for his behavior or its consequences.

But even if Anderson has a "disease" and so is not responsible, meaning in this context "at fault," this does not imply that the *company* should be held responsible or liable. Anderson's vulnerability to disappointment and the resulting "disease" are his bad luck, if they are not his fault. Why should the company automatically have to pay?

Moreover, the assumption that Anderson is not responsible, because diseased, is unsound. We often hold a person responsible for imprudent conduct that brings about a disease; additionally, we may hold a person responsible for failing to take steps to prevent the disease from doing damage to oneself or others, or for taking steps to limit or cure the disease. The word "disease" is not an incantation that gives blanket relief from all responsibility for the damages it does.

However, one might assume that "alcoholism" is a very special disease in that it destroys one's "will-power" and renders one incapable of acting responsibly. But this is contrary to the assumption shared by medically oriented treatment programs, as well as by such major alcohol-abuse programs as AA. Such programs rely on the alcoholic's initiative in seeking and entering treatment, or they use inducements to elicit voluntary entrance and then rely on the alcoholic's self-discipline which requires a large amount of "will power."

Finally, is it true that "alcoholism" is a "disease"? Consider the following facts: there is no scientifically accepted basic understanding of the origins, causes, or nature of "alcoholism"; nor is there a scientifically demonstrated method of "cure"; nor is there even any generally satisfactory analysis of what is meant by "alcoholism." The slogan "alcoholism is a disease" represents not a scientific discovery or a generally accepted scientific hy-

pothesis; it represents the *faith* of many health professionals that a "solution" to the problems of alcohol abuse will some day be found by medical science.

But not every social problem is rooted in physical disease. At present, the evidence to be found in the enormous literature on alcohol and drug abuse reasonably allows one to suppose that there is not a single causal process, but a complex set of problems having biological, psychological, social, and cultural dimensions.

More to the present point, no one can satisfactorily explain in specific and scientific terms why Anderson started to drink excessively, why he kept it up, or what would get him to stop. He is to be pitied. It is a misguided pity, however, that assures him that he is a helpless victim, with no responsibility for his drinking problems. It is morally corrupting, and legally unsound, to assure him that it is the company's fault. It is simple deception to give him to understand that these assurances are grounded in a modern scientific understanding of alcohol abuse.

COMMENTARY

by LUTHER A. CLOUD

Alcoholism is a disease, and has been accepted as such by the American Medical Association and by virtually every major medical and scientific body in the world. Criteria for the diagnosis of the disease of alcoholism were published in 1972 by the National Council on Alcoholism, and are in use by the medical profession.

Boyd Anderson's claim, however, is being made on a faulty premise. Since alcoholism is a physiological disease entity, it would be manifestly impossible for the company to have "given" Anderson that disease, just as it would have been impossible for them to have given him a cancer or have caused him to have a weak heart.

Anderson's job *did not require* him to drink. He was required to take out clients and entertain them. His drinking was a matter of his own choice. About one out of ten individuals who drink appear to have a biochemical or physiological "predisposition" to alcoholism. Obviously, Anderson was one of these individuals.

He contracted alcoholism, not as a result of his drinking per se, but because of a physiological difference which, coupled with his drinking, gave him the disease of alcoholism. The company can hardly be blamed for this situation.

Anderson might have had a valid claim if he had based it on the manner in which the company handled the situation that resulted from his alcoholism. Instead of telling him "to accept early retirement," the company would have been better advised to offer him a firm but fair choice between accepting treatment for his disease (alcoholism *is* treatable), or accepting the alternative early retirement.

Treatment for the disease of alcoholism should have been covered by the group health insurance policy just as it would cover treatment for any other disease.

Many firms have programs which offer alcoholic employees a choice between accepting the disciplinary consequences of the poor job performance caused by their alcoholism. These companies consistently report long-term, stable recovery rates from 70 percent to 85 percent and occasionally even higher. Any company that does not have such a program leaves itself open to suits like Anderson's, which can be extremely costly to the company, even if it wins in the end.

COMMENTARY

by SALLY GUTTMACHER

The issue of legal liabilities is the least interesting raised by this case. It seems unlikely that many courts would recognize Anderson's claim. Anderson, it can be argued, accepted the rules, and willingly took risks for the possibility of substantial rewards. Yet he claims that in the course of his work he became damaged by as well as dependent on the company. In effect, Anderson declares illegitimate the rules he had previously accepted and seeks compensation through the only means possible—the legal system.

His case is weak. Unlike occupational disease such as black lung where the line of causality is clear, self-destructive behavior (suicide, drug addiction, chronic excessive eating, drinking, or smoking) is generated by a combination of factors —some work-related and some not. In addition, most would argue that chronic excessive drinking is to some extent voluntary. Perceiving the alcoholic simply as a victim of his "disease" denies the notion of his autonomy, an approach that may actually impede rehabilitation.

The more subtle and engaging questions emerge from viewing self-destructive behavior as a response to, or even sometimes a rebellion against, the inhumane and pathological conditions of our lives. How does self-destructive behavior become a commonly selected option for dealing with stress or failure? And who bears the moral responsibility for this situation? How are such disorders related to work in our society, and how might work be restructured to decrease the risk of such outcomes? Finally, why are there so few real options outside the work situation through which an individual can develop self-esteem and taste success?

Even though it may be difficult to argue that an individual corporation should be held *legally* responsible for a pattern of behavioral response that is clearly a product of broadly based social habits, these habits are not mere accidents. They are covertly encouraged, for example, by being presented as a legitimate way for adults to deal with stress. (One needs merely to note in one evening of commercial television viewing the proportion of scenes involving social interaction in which alcohol and cigarettes are common props.) Through a myriad of such linkages—each perhaps weak in itself, but powerful in the aggregate—the corporation acquires responsibility in its broader role as part of the ruling segment of the society that establishes "the rules of the game" and even creates and encourages life styles for its own benefit.

Therefore, a given corporation cannot be permitted to retreat conveniently behind the claim that it too is the victim of the iron laws of the market. This may be a legal defense, since laws are codifications of the rules of the game, but it fails as a moral defense given the rudimentary facts that modern corporations exist chiefly to make profits. To the extent that these profits are at the expense of the well-

being of workers or of consumers, corporations can be charged with behaving immorally.

Certainly, within the current rules many will argue that the corporation acted fairly, even humanely, in its dealings with Anderson. While there is some merit in this view, the motivation behind the corporation's action is another question. With relatively high levels of unemp' many workers carry the status of expendable, easily replaceable commodities. That Anderson was offered other options by the company is not simply testament to corporate compassion, but rather an indication that he belongs to a special class of workers who, because a substantial investment goes into their training, are perceived as (human) capital. Thus, as with fine-tooled machinery, some trouble is taken to see that they continue to function in some productive capacity. At the very least, the company will make an effort to see that those with problems, such as Anderson, are handled in ways that do not demoralize the others.

Because Anderson must bring the case to court and bear the burden of proof, the issue becomes depoliticized. Accepting this way of proceeding, moreover, ratifies the view that problems such as alcoholism simply represent the unintended, unforeseen, and unwanted consequences of an essentially well-functioning system. This is a curious response to a problem that now affects 10 percent of our work force, a statistic that may be interpreted as an indicator of a serious malfunction in our way of life.

With these rates in mind, we must ask who bears the risks in our society, and, if these risks are too great, who has the power to restructure the system and decrease the risk? By presenting the problem as a question of individual corporate responsibility, we lose sight of its broader implications. And by permitting corporations in general to shift the price and responsibility for the human wastage that is a by-product of our whole economic system onto public institutions, we ignore the need for a basic reorganization in the structure of work.

Mentally Retarded Hepatitis B Carriers in Public Schools

In compliance with a court order that requires placement of mentally retarded residents of a state institution into less restrictive community settings, New York State officials have begun to place a number of school-aged children in family and foster homes and other community residences in New York City. They have also arranged for these children to attend special education classes in public schools.

In 1977 a teacher of several of these children became infected with type A hepatitis. An investigation by the New York City Department of Health concluded that the teacher's type A hepatitis did not appear to present a serious health problem. However, a hepatitis B problem might exist because of the infectious nature of this disease, which almost all the children in the institution had contracted.

Hepatitis B is a virus which may have a debilitating effect upon the liver and has been linked to cancer. After a several-month period of incubation the virus, in a susceptible person, may reach the acute state. In some of these cases, involving jaundice and inflammation of the liver, the disease is very serious and can even lead to death. In other cases, especially among children, the acute phase may be very mild, and is often mistaken for flu and a fever. There is no known cure for hepatitis B, although a vaccine is being tested and may be available within four years.

After the acute phase has passed, there may be one of two outcomes. If the patient has built up sufficient antibodies, the virus will be eliminated; and the individual will be immune from the disease indefinitely. If, however, the patient does not create sufficient antibodies, he or she may appear clinically healthy but, upon careful examination, will be found to be "carrying" the virus (antigen) in his blood. This carrier can transmit the virus to another, who may also become a carrier, without either of them showing clinical signs of illness. For example, approximately 30 percent of the residents of the state institution are now immune, and about 60 percent are carriers.

As a result of the Health Department's report, a task force was formed to conduct a study to determine the extent of the hepatitis B problem. All children in special education programs where known hepatitis B carriers were present were included in the study—a sample of about 450 students. Of that number, forty-four were already known carriers, because they had come from the institution, where they had already been tested. The tests on the remaining children identified five additional carriers. There was no way of determining how they contracted the virus, but suspicion immediately focused upon contact with the already known carriers.

This explanation seemed likely because of the unhygienic behavior displayed by many of the identified carriers. The virus is transmitted through body fluids—saliva, blood, etc. Among the students there was hand-to-mouth contact, drooling, bleeding gums, biting, and scratching.

As a result of this study the Department of Health recommended that the Board of Education test students at regular intervals, and classify them as "carriers," "immunes," or "susceptibles." Susceptible children were to be grouped separately from carriers, in classrooms and lunchrooms, and were to receive special supervision to avoid contact with carriers. (Some of these children are particularly susceptible because of poorly developed immune systems.)

Some parents, as well as representatives of the teachers' and the staff's unions, opposed these guidelines. They claimed that it was unfair to subject the "susceptible" group to restrictions. They also argued that the plan could never be implemented because there was insufficient personnel to provide the required close supervision. They believed that the "carriers," not the "susceptibles," should be segregated. They proposed removing the forty-four identified carriers from the public school and sending them to education programs at the state institution. Because children in special education classes have so little contact with normal school children, this group urged, the complete absence of such contact would have a minimal effect, if any, upon them.

The staff at the state institution opposed this idea. They argued that contact with society, even in a limited way, is essential to the development of a mentally retarded child. Moreover, they were not convinced, given the uncertainty of the data about the susceptibility to infection of persons with hepatitis B antigens, that restrictions upon either the susceptibles or the carriers were justified. They maintained that control measures should focus upon good hygiene practices, prohibitions against sharing toilet articles, and special handling of blood-contaminated items.

Should the Board of Education segregate the carriers from other students? Or should they maintain them in the classrooms? On what grounds can either decision be justified?

COMMENTARY

by ROBERT PLOTKIN

This case presents a classic problem in contemporary terms. Forty-four former residents of a mental retardation institution who now live and attend school in the community have been identified as hepatitis B carriers. Should the Board of Education segregate them from the rest of the special education students in the public schools by returning them to the institution for their education? The forty-four assert

their right to live and be educated in the most normal environment appropriate to their individual needs. Their claims are in apparent conflict with the Board's public duty to protect the health and welfare of other students, the teachers and staff who have a right to avoid exposure to a communicable and possibly fatal disease. Which of these competing interests should be accorded the higher priority, and for what reasons?

Where there are competing liberty claims, the task is to determine the relative worth of the interests. One must choose which interest represents the greater good by comparing the degree of risk to the public health with the extent of the proposed restrictions upon individual liberty. Where known risks to the majority present an imminent and substantial threat to the public, it is more likely that restrictions upon individual autonomy will promote the greater good. But where the potential risks are unclear and the threat to the public is speculative, interference with individual liberty becomes the lesser good. A comparative analysis of the risks and rights at stake in this problem leads to the conclusion that the forty-four identified carriers should *not* be segregated from their fellow students.

The public health risk is not sufficiently clear to justify exclusion. Although hepatitis B can be fatal, death is statistically rare. It is not a readily communicable disease; it is transmitted primarily by blood contact. While other modes of transmission may exist, the evidence for the probability of contagion remains ambiguous. Whatever the dangers, the degree of risk appears to be related inversely to the cleanliness of the affected environment and the participant's personal hygiene—factors that in this case are controllable through the provision of proper educational programming, staffing, and classrooms.

The degree of risk that is actually involved in contacts with hepatitis B carriers is also uncertain, because it is not now possible to separate carriers who will transmit from those who will not. Interestingly, the incidence of hepatitis B—either active cases or carrier cases—among the institutional staff where these students resided is not unusual or significant. This demonstrates that even prolonged exposure in an area highly concentrated with carriers does not necessarily result in infection. The forty-four identified carriers could easily go through their entire lives without infecting a single person.

Moreover, even if the formerly institutionalized students are returned to the facility, the risk of infection, whatever it may be, is not significantly lessened because carriers also appear in the students who were never institutionalized. In other words, identification as a hepatitis B carrier is not synonymous with one's status as a former resident. It is just as likely that, if the larger group of students were subjected to the same intensive screening devices, it too would include a number of carriers. While one might speculate that in the larger group carriers resulted only from contact with one or more of the forty-four former residents, there is simply no way to be sure that they were not undetected carriers prior to that exposure. Removal of the forty-four may alleviate somewhat the already minimal risks of continuing exposure, but it is surely impossible to quantify the level of that reduction.

Thus, the public health rationale advanced to justify the segregation of the formerly institutionalized carriers is at best tenuous, and in any event the solution proposed for protecting the public's health is inadequate because some carriers will still remain in the public schools. Arguments favoring the segregation of the minority group are more likely based improperly upon real-world economic and administrative concerns: It is cheaper and easier to isolate than to accommodate.

Balanced against these public welfare concerns are the principles of autonomy and respect for persons. The rights infringed by a decision to again segregate the formerly institutionalized persons—rights of liberty, association, and free expression—are among the most fundamental components of individual autonomy, and the severe restrictions on their physical liberty are self-evident. In addition, these students will be deprived of positive emotional and environmental influences, their future intellectual and social growth will be stymied, and already developed life-skills may atrophy. The speculative "risks" to the public health pale when balanced against this enormous loss of individual liberty and personal growth.

Significantly, numerous court decisions and federal and state laws mandate that handicapped children live and be educated in the environment that is most normal and appropriate to their individual needs. Placement in the public schools had previously been determined as legally proper for these forty-four students, and a subsequent decision to override those assignments must be based upon evidence more compelling than that presented here.

Finally, there is an additional, important argument against the segregation of these particular students. Principles of social justice demand that their right to live in the community be accorded special deference because the comparative value of their freedom is greater than that of the general student body. They were involuntarily placed in a state-operated facility, ostensibly "for their own good." While there, they were actually exposed to harms such as the hepatitis B virus, and their human and medical needs were neglected. They never agreed to these arrangements, and while some elements of society-at-large may have "benefited" from their confinement, they certainly did not. The public has unreasonably interfered with their pursuit of a normal life. It must now redress that injustice by demanding particularly convincing justification before they are again excluded and stigmatized anew as "carriers." Thus, not only must general principles of ethics and law forbid any segregation based upon so flimsy a public health rationale, but the renewed institutionalization of these children deserves special resistance.

The enormous discrepancy between the speculative "good" to the public that may be achieved by isolation, and the actual harm that will likely be experienced by the forty-four identified carriers, prohibits excluding the carriers from the public schools. The Board of Education must devise alternative preventive health methods that will better accommodate these competing interests.

COMMENTARY

by **H. TRISTRAM ENGELHARDT, Jr.**

If there could be a general moral maxim for attitudes towards the mentally retarded, it should be this: they should not on principle be treated differently from other humans. However, the term "mentally retarded" misleads as much as it informs, gathering together in one category

individuals of diverse abilities, interests, and difficulties. Moreover, like the medical terms syphilitic and leper, it tends to alter radically social reality, casting its bearers in sick roles that often lead to unwarranted isolation. Of course, all disease language is evaluative and to some degree performative. That is, disease language places a value upon a particular human state and assigns individuals in that state a place in a social world of cure, care, prevention, and quarantine. Thus, being called mentally retarded is like being deputized by the sheriff: the people in the world around you at once are authorized to look at you in a different fashion. At times such evaluations are inappropriate in the sense that they lead to the loss of important human goods. Moreover, as one would expect in all complex human situations, it often occurs that human goods are put at jeopardy in a fashion that not all can be realized, even given the best choices. Such appears to be the case here.

The case of the deinstitutionalization of these mentally retarded individuals raises at least the following ethical concerns:

1. One wishes to treat the previously institutionalized mentally retarded individual as fairly as possible, giving him as normal a life context as feasible.

2. One wishes not to expose unconsenting teachers and children to the dangers of hepatitis B or perhaps, in addition, cancer (if such be a sequela).

3. One is concerned as well not to expose unconsenting foster parents to the risk of hepatitis B and the possibility of cancer.

4. Similarly, one has an interest in protecting the public against dangers of increased exposure to hepatitis B and cancer.

5. With reference to points 2-4, one should out of regard for concerns of fairness wish to determine what the implications of any policy choices with regard to the mentally retarded would be for relevantly similar populations (e.g., nurses working on hemodialysis units who may become active carriers of hepatitis B virus).

This constellation of issues is similar to the concerns with regard to maximizing value over disvalue, and of protecting the innocent against unconsented-to injury raised by the disputes concerning the safety of nuclear power plants, recombinant DNA research, and industrial pollution. There are disputes concerning the actual risks involved. There are arguments with regard to the rights to forebearance of individuals who might be subject to injury. One in short is confronted with a scientific issue with a heavy ethical and political overlay, so that the questions appear in part to turn upon empirical issues and in part on ethical questions. With respect to the latter the basic issue concerns determining the point at which the interests of one group to exercise their rights or to pursue their goods is defeated either (1) by the injuries caused to another group by the first group, or (2) by the rights of the second to the forebearance of the first. This determination, in turn, will at least in part be a function of the facts of the matter. What indeed are the possible injuries?

I believe that an answer can only be reached given a better appreciation of the empirical data involved, as well as of their softness. Such demurral is, I believe, appropriate in that there appear to be possibilities of two forms of technologically resolving at least some elements of the controversy. As a result I will for the most part simply attempt to clarify the geography of the problems.

The only major point I will forward is that whatever conclusions one reaches with regard to quarantining the mentally retarded should be explored with regard to their implications for our conduct with respect to other similar populations who are likely to be active carriers of serum hepatitis B virus (e.g., dentists, nurses working in renal dialysis units, etc.). In many such cases, it might, however, be properly rejoined that such individuals, given their general level of cleanliness, etc., do not represent a public health menace of the same proportion as the mentally retarded children in question.

To resolve this issue one would need to have made judgments on the following points:

1. How soon will a vaccine for hepatitis B virus be available and how safe and effective will this new vaccine be?

2. What are the actual benefits to the mentally retarded children of deinstitutionalization?

3. What would the consequences be of delaying deinstitutionalization until a vaccine is available?

4. Can antigen tests be used to identify the actual active carriers of hepatitis B virus and therefore decrease the number of individuals concerning whom one need have concern that they might transmit the disease to others? If this group is small enough, can they then be adequately "quarantined" in special classrooms in the regular school system without losing the benefits of deinstitutionalization? (See question #2 above.)

In short, one has a case of different groups each concerned that it not be forced to cede its rights, on the one hand to develop its potentials, on the other hand not to be exposed to the risk of serious disease or death. One has, in short, a head-on conflict between rights. However, here there is the possibility of a technological fix, a test for true, active carriers and the possibility in the relatively near future of a vaccine. In short, the problems focus upon the question of a delay or of a compromise through some halfway procedures in an interim period.

In any event, one will need to give to all foster parents full information about their potential exposure to risk. Moreover, one will need to be assured that high-risk school personnel are adequately protected before they are exposed to a substantial risk of morbidity and mortality. This would include, for example, teachers who are older, have diabetes, congestive heart failure, or are post-menopausal. For such individuals there are good grounds for believing that exposure to such a risk is an exposure to a substantial danger of serious illness and death. There are probably few who would contest their rights to be protected. It is in other populations, where the risks are more remote and less severe, that the answers are not as clear. In short, as in most complex bioethical quandaries, the problems are as much questions of fact as of principle.

Health Risks and Equal Opportunity

Mark Dalton, a thirty-two-year-old histology technician, was hired six months ago by a large chemical company. He has proven to be highly skilled and produces excellent slides at a rate exceeding his co-workers. Recently, after he took a week's sick leave, the employee health department nurse was surprised to learn that he is suffering from chronic renal disease. His entrance medical questionnaire did not mention any problem.

Since his job requires exposure to chemical solvent vapors at levels permissible by OSHA regulations, the company physician counseled him that continuing exposure to the vapors could exacerbate the disease.

Company management found a job for which he would qualify at the same rate of pay; but two current employees, one of whom is female, who are eligible for promotion are interested in the job. Both have better training and longer service with the company than Dalton.

Management has grounds for dismissing Mark on the basis of false representations about his health. If Dalton is given the available job to protect his health, it is likely that the woman employee who is better qualified will file a complaint charging discrimination with the Equal Employment Opportunity Commission.

Should Dalton be fired? Given the safer job? When three workers have a valid claim to a job, one based on health, one on seniority, and the third on equal opportunity, which should prevail? —Robert E. Stevenson

COMMENTARY

by **DEBORAH G. JOHNSON**

This case raises a set of questions about the relationship between employers and employees. Just what rights and obligations each party has with respect to the other is a matter that is only vaguely understood and only partially defined by law. Nevertheless, assumptions proliferate on both sides. Employers assume, for example, that employees should have a certain amount of loyalty to their employers; and employees assume that they should have the right to an appeal if they are treated unfairly in evaluation and promotion.

In this case, if Dalton knew of his condition and failed to report it on his application form, then he falsely represented himself and the company's commitment to him is voided. In a sense, the application form becomes part of the tacit contract between employer and employee. The company agrees to employ the individual, to provide certain benefits in exchange for work of a certain type and quality, but the employer agrees to do this on the assumption that information given by the applicant is true. The company would not have hired Dalton if they had known of his condition; thus, it does not have a duty to continue to employ him. But, this does not mean that they must or should fire him. Since he misrepresented himself, it is morally permissible to fire him, but continuing to employ him does not violate a moral norm.

Companies that hire individuals to work in environments that are unsafe or pose a threat to health have a duty to inform those workers of the risks involved. Failure to inform workers whose health is at risk or will be at risk is a violation of employees' bodily integrity. Violating employees' rights to control what is done to their bodies is roughly the same as placing people at risk in an experiment without their consent. However, companies should not make decisions for their workers. To do this would be to deny the autonomy of individual workers and to disregard their ability to judge what is in their best interests. Each worker should decide for himself or herself whether or not to take the risks involved. Workers can do this only if they are given information about the risks, and therefore companies have an obligation to so inform workers.

In this case, since levels conform to OSHA standards, the company has fulfilled its obligation by counseling Dalton that continuous exposure to the vapors would be dangerous to his health. If Dalton is a mature, sane individual and wants to continue working, the company may continue to employ him. Of course, if Dalton chooses to take the risks and his condition worsens subsequently, the company should not be considered liable for compensation. Dalton would have accepted the responsibility for his condition by accepting the job knowing the risks.

If Dalton prefers another job in the organization, the company may provide such a job but, as already indicated, they are not obligated to do so. It might be good for Dalton and might be good for the company but morality does not demand that these goods be brought about. The company would have an obligation to find an alternative position for someone who developed a renal problem while working for the company, and this obligation would be even stronger if the condition was caused by the work environment, but this is not the case with Dalton. In this instance, if people already employed by the company are qualified for an available job, then the company has a stronger obligation to promote these employees according to rules that are operative in the company.

This analysis suggests that companies have obligations to their employees but that these obligations are voided if workers misrepresent themselves. It suggests that the company has no obligation to act paternalistically, that is, to protect employees from themselves (which is what the company would be doing if it refused to let Dalton work at a job of his choice, even when he knew the risks involved). Rather, the obligation is to provide information to employees so that they can make autonomous decisions. But circumstances might arise when the claims of individual employees would compete.

While Dalton's claim to the job does not compete with the claims of the other workers, the rights of a worker with seniority may well conflict with those of a woman. I do not think we can decide in advance how companies should resolve all such cases. The merits of each claim must be weighed in the light of given circumstances. Who has the stronger claim will depend on such matters as the type of job available, the merit of the employees, the company's

past record on discrimination, and the firm's stated policy on seniority. This does not mean that companies should disregard a claim to equal opportunity. On the contrary, a commitment to equal opportunity means an obligation to consider the strength of an applicant's claim on the basis of relevant criteria.

COMMENTARY

by KNUT RINGEN

English and American common law traditionally have held that the employer is responsible for the conduct of work, including the provision of a safe and healthy workplace. This common law principle underlies the Occupational Safety and Health Act of 1970.

However, absolutely safe and healthy workplaces do not exist today, and they will not exist in the future. Given the reality of residual risks, particularly associated with chronic diseases, safety and health in the workplace must be a responsibility shared by employer and worker.

How can this responsibility be shared fairly? Employers through their associations continue to insist that they should have absolute control of the workplace, including the right to restrict information about hazardous substances. For this reason, many workers, who are forced to be responsible to some extent for their own health, are not informed about the hazards that they are exposed to in the workplace.

However, we can assume that Dalton was knowledgeable about the risks. This case therefore raises the following issues of responsibility:

- Did the worker act irresponsibly in not revealing the chronic renal condition at the time of employment, and should he therefore be fired?
- Should the worker be moved to another job for health reasons?
- If moved, should he be given precedence over other candidates for the available alternative job?

Legally, a worker is required to give truthful answers to preemployment medical questions. In reality, however, the worker should be allowed some leeway, just as the employer is given leeway in providing a safe and healthy workplace. Most workers know that they will not be employed if they provide information about having a chronic disease, because the employer does not want to risk being held liable if the worker gets sick. Thus, even where there is no association between type of work and the worker's chronic disease, the mere presence of the disease (or even a personal disease risk factor) may preclude employment. We must expect that some workers who understand this situation will not be totally candid in answering their pre-employment medical questionnaire. However, we would expect the lab technician to be more responsible for assessing the risk and potential hazard than a less informed worker.

Justification for firing the technician on these grounds thus may or may not exist. We cannot know for sure if the worker knew of his renal condition at the time of employment. We also cannot be sure that he knew the condition could be exacerbated because of his lab work. The company physician seems to acknowledge that the contribution of workplace exposure to the disease progression is potential, but not certain. Given this caveat, justification could exist for the worker not to admit his chronic disease. It would be unreasonable to expect him to jeopardize a specialized career by revealing medical conditions that he might judge unrelated to his work.

Medical removal protection is central to the current debate on occupational health regulations. This principle was legally promulgated for the first time in OSHA's initial occupational safety and health standard for asbestos exposure and it is an essential element of the recent standard to protect workers from exposure to lead (43 *Federal Register* 52952, 1978). Under the lead standard, a worker may be removed from his or her regular employment on the basis of an examining physician's medical opinion or when the measured level of lead in the worker's blood is high enough to indicate a "material impairment to health or functional capacity." When removed under this provision, the worker will receive compensation in the form of maintained earnings, seniority, and other benefits.

Although the lead standard requires only temporary removal of the workers and may not necessarily apply to permanent displacement, it clearly signals a new direction for the protection of worker rights. It represents a means of last resort to protect individual workers where the established permitted level of exposure to risks is inadequate. OSHA standards, including the lead standard, allow some exposure because it is not feasible to achieve a zero level and they may be fairly adequate for most workers. However, individuals who are especially susceptible to a given toxic effect will suffer disease even when exposure falls within accepted limits. It is these individuals that the medical removal provision will protect.

A few employers voluntarily offer job security and medical removal. In a few union contracts (notably the Steelworkers) medical removal is part of the benefit program. However, most workers know that they will lose their jobs and suffer other adverse employment effects because of an abnormal medical finding. The workers realize that once fired for medical reasons they will have a very hard time obtaining similar types of work and may even be investigated by companies that monitor workers' compensation claim files (see *Business Insurance*, June 9, 1980, p. 27). And workers have long known intuitively what was documented recently by the Department of Labor Interim Report to Congress on Occupational Diseases. According to that report, only 1 to 5 percent of job-related diseases are covered under current workers' compensation programs.

The ethical employer should also recognize the limitations of existing OSHA standards and the inequity of firing for medical reasons the worker who is denied general health protection under existing standards because of unique susceptibility. In other words, the same latitude that is allowed the firm in operating at levels of exposure that will fail to protect everyone should apply to the workers who cannot tolerate those exposures. In this case, the employer acted correctly in voluntarily providing medical removal protection.

Finally, the case raises the issue of preferential treatment. If the lead standard is cited as the precedent, preferential treatment would probably favor the worker with the medical condition. The worker is not at fault for the medical condition, and to deny alternative employment would be to place the burden on him. Also, various medical problems today qualify for affirmative action under federal law, and medical removal could fall into this category.

Should States Require Child Passenger Protection?

Motor vehicle accidents are the leading cause of death and injury in children over one year of age in the United States. In response to this problem, bills have been introduced in the legislatures of more than twenty states that would require children to be restrained when riding in motor vehicles. Details such as age limits and types of allowable restraint devices have varied with the individual proposals. Laws have been passed in Tennessee and Rhode Island requiring child passengers to be restrained under certain circumstances. In both these states, as well as in many other states where similar laws have been proposed, objections have been raised on the basis of individual and family rights.

A state legislative commission has drafted a Proposed Model Law: Every driver transporting a child under the age of five years in a motor vehicle registered in this state and operated on the roadways, streets, or highways of this state shall provide for the protection of the child by properly using a child passenger restraint system meeting applicable Federal Motor Vehicle Safety Standards. Is such a law a necessary protection, or does it violate due process, privacy, and the right of parents to raise children as they see fit? Does it also discriminate economically?

COMMENTARY

by JEROME A. PAULSON

Motor vehicle accidents are the leading cause of deaths and injury among children over one year of age. According to the National Safety Council, over 800 children younger than five years of age are killed each year as motor vehicle occupants. At the National Conference on Child Passenger Protection held in Washington, D.C. in December 1979, S.P. Baker reported that more than 50,000 children younger than five sustained injuries severe enough to require an emergency room visit. The monetary cost for these deaths and injuries is well over $100 million per year. The magnitude of the problem makes it a public health issue; therefore the state should use its police power to attempt to resolve or ameliorate the situation.

According to recent studies, various restraint devices have the potential for reducing injuries by 70 percent and deaths by 90 percent. Yet, only 7 to 15 percent of children ride restrained.* Apparently parents—through ignorance or inappropriate evaluation of the risk-benefit ratio—have chosen not to use these devices.

When accidents occur, the state is called upon to provide costly services. It rescues the children, transports them to the hospital, provides acute medical care, and in some instances long-term rehabilitation. If permanent disability occurs, the state may even provide monetary support to a child for life. Even when parents carry health insurance, many policies are not limitless, and the state eventually may bear some cost. Because the state provides these services, it has the right and responsibility to insist on a means of injury reduction such as seat restraints.

A small number of motor vehicle accidents are directly attributable to the activities of unrestrained children in cars.** Drivers may lose control of their vehicle when an unrestrained child falls on them while the car is rounding a bend or when a child climbs over a seat and accidentally kicks the driver in the head. As a result, people in other vehicles may be injured or killed. The state has the responsibility to protect those other people. Because the seat restraint law would promote the safety and welfare of the public as well as of the individual child, such a law would satisfy the due process clause of the 14th Amendment to the Constitution.

Mandatory seat restraint laws would not represent an invasion of privacy. There are fewer limits on a state's involvement in activities in a motor vehicle than in a home. The motor vehicle is used on the highway, which the states traditionally have the right to regulate. In some states, where driving on a public thoroughfare is a "privilege" and not a "right," the legislature has even more latitude in prescribing appropriate rules. Parents do not have absolute or unlimited rights over their children. They have a responsibility, by common law, to provide for their child's health and safety. While adults may be able to make their own decisions regarding safety, children younger than five do not have that capability. They are at their parents' mercy. When parents do not discharge this responsibility, the state may step in and fill the role of *parens patriae* as they have done when young children are neglected or abused, or when parents fail to have their children immunized as required to attend school.

Seen in this light, the mandatory use of child restraint devices does not interfere with family rights. Rather, it helps to preserve the family unit by keeping the child safe and protecting the family from the injury or death of a child with its attendant financial and emotional costs.

Unfortunately mandatory seat restraint laws discriminate economically because parents with limited incomes may not be able to afford the devices. However, other laws related to health and safety are similarly discriminatory. These include immunization laws, laws requiring snow tires and chains during snow emergencies, and

*R.G. Shertz, "Epidemiology of Childhood Motor Vehicle Related Accidents," Twenty-third Stapp Car Crash Conference, 1979, p. 291; A.F. Williams, "Observed Child Restraints Use in Automobiles," *American Journal of Diseases of Children*, 130 (1976), 1311.

**W.L. Hall and F.M. Council, "Warning: In Cars, Children May Be Hazardous to their Parents" Health. The Role of Restraints in Preventing Collisions," *Proceedings* of The American Association for Automobile Medicine, October 7-9, 1980.

laws requiring smoke detectors in private residences. Yet such discrimination has not precluded their promulgation. Overall, no individuals rights issues would convincingly preclude a mandatory seat restraint law.

COMMENTARY

by LAURENCE THOMAS

There are certainly things that parents morally ought to do in connection with their children, but that the law should not require them to do even if it is a matter of life and death. For instance, in the interests of safety, parents should not leave their children alone for extended periods of time; yet laws should not require this of parents.

Children are raised by their parents, and not by the state. There is a limit to how much the state can *force* parents to do on behalf of their children without undermining the respect that children have for their parents and, therefore, parental authority. In the absence of this respect, the family cannot survive in any form, just as democracy cannot exist if people do not largely respect the laws that govern them. If we force far too many parents to do far too many things that they do not wish to do on behalf of their children, we may very well undermine both the family and democracy at a single stroke. And this may be too great a price to pay for child safety.

But matters are not nearly as bad as this case study implies. First, it is false that a child has a high probability of being injured or killed while riding in a motor vehicle. Rather, there is a high probability of either happening if the motor vehicle in which the child is riding has an accident. Second, it is not that far more children than adults die in motor vehicle accidents. Rather, a great many adults die from other causes, which generally do not affect children—heart disease and cancer, for instance. So we are not even talking about an event that singles out children for injury or death, let alone one that inflicts injury or death upon large numbers of children.

Thus, a child's life is not placed in imminent danger by not wearing seat restraints. That is the rub with laws requiring parents to restrain their children in motor vehicles. There must be strong limits on what the law should require parents to do on behalf of their children when the lives of children are not in imminent danger. Otherwise, the essential ingredient of parent-child relationships is imperiled, namely that children see that a parent acts on their behalf out of love.

Child safety is obviously very important, but it must be balanced against other factors, the most important among them being autonomy. If children are to develop into autonomous beings, if they are to acquire a sense of self-command, then parents must allow them to venture out on their own and to take risks. Parents who insist upon protecting their children from every possible danger, as opposed to imminent danger, do not make the best parents. Life and the quality of life must be balanced against one another.

Suppose we know that the genetic make-up of some otherwise normal individuals will result in their producing infants with spina bifida, a severe birth defect that causes immense suffering. Morally such people ought not to produce children. But should they be sterilized against their will in order to prevent conception? Although sterilization would prevent enormous suffering, we hesitate because such action seems to constitute a flagrant violation of personal autonomy.

Compare this hypothetical story with a real one in which Judge John P. Flaherty refused to order that David Shrimp undergo a bone marrow extraction so that his cousin, Robert McFall, could receive a transplant operation (*Hastings Center Report*, Feb. 1980, p. 11). If the intended beneficiary had been Shrimp's child, rather than his cousin, perhaps morally he ought to have undergone a bone marrow extraction. But certainly it would not have been morally permissible for the state to force him to do so, even if, as was the case with McFall, the patient's life was at stake (McFall died about two weeks later); and even if it was clear (as it was not with McFall) that the patient would survive if the transplant were done.

Within a fairly wide range, it is more important that children see themselves as the objects of much parental love and regard than that they be protected from all of life's hazards. Legislation that loses sight of this will, in the long run, benefit neither child nor society. Accordingly, the heightened concern that should guide parents in the case at hand must be achieved through education rather than legislation. For forced concern is no concern at all.

A Police Informer in a Hospital Bed

The head of the medicine department in a large county teaching hospital received a telephone call from the local District Attorney requesting assistance. The community had recently been shocked by the gangland-style execution of several innocent bystanders present at the scene of a robbery. Through a usually dependable underworld contact the DA had received information concerning the identity of the suspected murderer.

Two days following the crime the suspect had been admitted to the county hospital for a drug abuse problem. The DA wanted permission from the department head to admit a "plant" with a hidden recorder to the hospital bed next to the suspect. The DA hoped that within the next several days the "plant" would gain the confidence of the suspect and engage him in conversation resulting in a casual but recorded confession. This recording would be admissible as evidence in a court of law.

Should the department head cooperate with this plan and admit the informer as a patient to the hospital?

COMMENTARY

by EUGENE V. BOISAUBIN

Two general conditions must be met if this plan is to be accepted. First, the suspect's medical care can in no way be compromised. Second, the morality of such a decision must be defensible.

Consider the first condition. Since the facility is a public teaching hospital, a resident in training rather than the department head would be caring for the suspect directly. In order to guarantee that no bias in care would occur, the department head would have to withhold the plan from the resident, which would be difficult. A modern hospital is a veritable Gordian knot of social interaction with therapists, social workers, and even students all participating in a patient's care. One cannot easily hide a patient in such a hospital, even a "planted" one. Some other personnel would have to be told. To guarantee success of the venture and limit deception, ideally only a few people would be involved, and these would be at a distance from the patient's immediate care. Public hospitals commonly care for felons, sometimes with guards present, and if these criteria were met, the suspect's medical care need not be compromised.

Unquestionably the greatest ethical problem is deception. The physician and other hospital personnel are being asked to participate in deceiving a patient. In this case, however, the deception may occur in a morally acceptable way. First, it is assumed that both a bed and personnel are available for the plan. Utilizing a "last bed" in a public hospital would be unacceptable. Second, although hospitals like churches have had episodic roles in history as sanctuaries, a hospitalized criminal suspect today is not entitled to protection from due process of the law. Generally a hospital staff should not deceive its patients, and the idea of routinely using the staff as an agency of coercion by the police is abhorrent. But deception in this case involves not medical care but only the hospital setting. The severity and the magnitude of the murder are enormous, with potential for recurrence since the perpetrators of such crimes are usually sociopaths.

Public institutions, including hospitals, have two major functions: serving and protecting the public. Hospitals and public health agencies serve patients with medical needs and sometimes protect either individual patients or the citizenry at large from disease. A patient with a highly contagious disease can be placed in custody with clear violation of individual rights if the disease is felt to be a threat to others in the community. The potential for murder is a real hazard for the public and a tax-supported hospital has a role in preventing public harm.

Large public hospitals are complex social entities buffeted by political strife but dependent for survival on the caprice of politicians and support of citizenry. These hospitals commonly reflect public values and problems as well as public pressures. When public fears and demands run high, as in this case, the pressure is real. Imagine a similar admission to an Atlanta hospital of a prime suspect in the recent slaying of black children. Crimes of this heinous nature demand justice and touch our most basic moral sensibilities to preserve the lives of innocents. In this particular case, the severity of the crime and the chance for its repetition are sufficient justification to allow deception of the suspected murderer.

What ought to be the role of the physician? As I have said, the physician involved in the plan should give up the responsibility of immediate care for the patient. The physician is being asked to create an environment for deception but not to directly compromise professional judgment or medical integrity. If he or she were a private citizen, we might allow and even encourage cooperation. The role of a physician should not preclude acting as a responsible citizen in assisting justice with an inhumane crime. Furthermore, in the *Tarasoff* tradition, it could be argued that the physician has the duty to try to prevent future harm to others.

In summary, the proposed plan is permissible because no compromise of the suspect's health care would occur and the potential violation of his rights, if he is innocent, is negligible. Allowing this particular deception in a hospital setting is not a dangerous precedent if safeguards are taken and the magnitude of the crime and the potential for recurrence are significant. Physicians need to be truthful with their patients but they also have an additional role as citizens in assisting justice and protecting innocents.

COMMENTARY

by EARL E. SHELP

This case places at issue the purposes, functions, and duties of hospitals and physicians in American society. One can speculate that direct and indirect external pressures could be exerted on a hospital administrator and medical director to accede to this request for cooperation with county agencies of law enforcement. The heinous character of the crime, the fact that the suspect was a drug abuser, a sense of civic duty, and a desire for justice could provide incentives to follow the suggestion of the District Attorney. Yet, these considerations are not sufficient from a moral point of view to justify participation in deceptive conduct. Students of criminal law should consider the legal questions associated with the proposal and the anticipated evidence.

Hospitals are social institutions committed to the care and cure of sick people. Public hospitals serve all on a basis of medical need without regard to social or moral merit. They are tangible expressions of human and social compassion in response to illness and suffering. Public hospitals have been associated with the educational function of the state by affiliation with schools of medicine. But, apart from housing and medically serving people in police custody, hospitals normally are not associated with the police function of the state. In a manner similar to physicians, public and private hospitals are perceived as agents of patients, dedicated to their best interests.

Physicians carefully defend their role as agents of patients, concerned to act primarily in the patients' interests. Trust between patients and physicians is heralded as a necessary condition to an optimal therapeutic relationship. Rules of confidentiality exist to promote and protect the privacy of communications by patients. Exceptions to confidentiality and privacy are recognized when required by due process of law or in order to protect the public's health. In the former instance, advocacy proceedings take place; in the latter, the necessary and sufficient conditions to require disclosure are matters of public record and patients are advised that disclosure is legally required. Certain medical specialties provide expert information in legal actions but, in America, they are not typically associated with the police function of identifying "deviants." Such conduct, it has been argued, would compromise medicine's commitment to serve primarily the medical interests of patients and to protect public health.

The District Attorney's request to place an informer in the bed adjacent to a suspected felon is in reality a request for the hospital and medical staff to share in a deception. Even if we can assume that the suspect's medical care would not be altered, that medical confidentiality would not be breached without authorization by a court, and that medical care would not be denied to anyone because of the unavailability of a hospital bed, deceit is morally objectionable. A manipulation of the routine environment of the hospital in order to facilitate a police function may appear prima facie warranted due to the particularly offensive character of the crime and the public nature of the hospital. But a more careful consideration renders this exception invalid. The declared central purposes of hospitals are to provide care and sanctuary (not necessarily legal sanctuary) for the sick. Conduct inconsistent with these purposes risks compromising the ability of the institution to fulfill its charter. Suspected or wanted criminals probably are always in the census of a county hospital. Their presence alone does not justify transforming a hospital from an institution of compassion into a lineup for the police. The proposed deception could be avoided by permitting the police to question the suspect. Other means, perhaps less convenient or efficient, of gaining evidence about the crime surely are available to the police. A decision to participate in the deception would damage the integrity of the hospital and hinder its ability to serve its constituency.

Physicians tend to object to deception except, correctly or not, in instances that have a therapeutic or beneficent objective for the patient (placebos and lying to relieve anxiety, respectively). This proposal does not satisfy either of these supposed excusing conditions. Further, there seems to be no "hard evidence" that the patient/suspect represented a threat to public welfare. The medical staff did not make a judgment of dangerousness on the basis of medical or psychiatric evaluation. Thus, a social duty for physicians to protect or warn does not obtain. Finally, medical consent to the deception would be incongruent with the declared interests and mandate of medicine.

The request by the District Attorney should be rejected because (1) deception is morally inappropriate conduct for physicians and hospitals, (2) the proposed action is inconsistent with the purposes and functions of hospitals and physicians, (3) it is not ultimately in the best interests of all concerned, (4) the duty to protect the public welfare in the proposed manner has not been shown, and (5) suspicion is not a sufficient reason to compromise the primary purpose and function of hospitals and physicians to care for the sick.